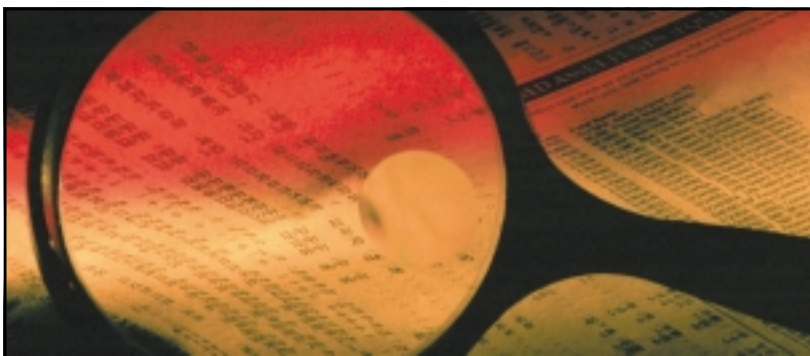


UTAH COMPREHENSIVE CANCER CONTROL INITIATIVE *PLAN*

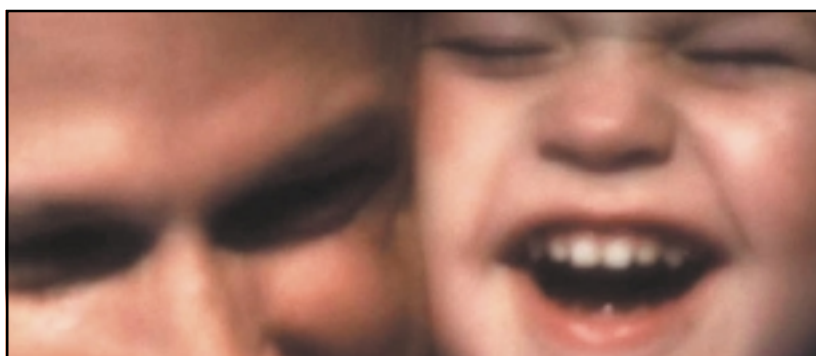
PREVENTION



*EARLY
DETECTION*



TREATMENT



*QUALITY
OF LIFE*

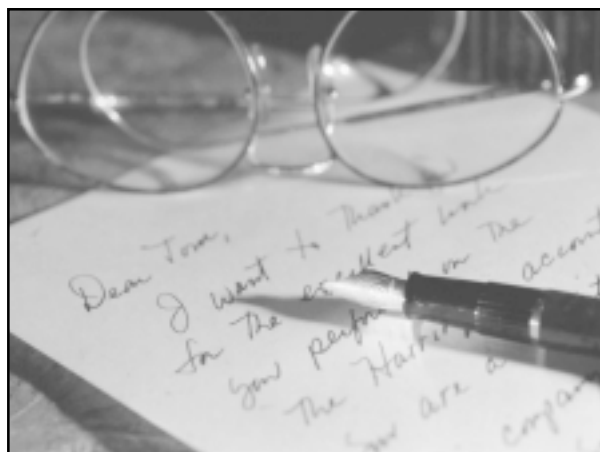


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ACKNOWLEDGMENTS

The completion of the Utah Comprehensive Cancer Control Plan was made possible through the efforts of numerous organizations and participants. From the beginning of the Utah Comprehensive Cancer Control Initiative (UCCCI), many have dedicated their time, knowledge and expertise to bring the plan to fruition. By sharing experiences and information, members' efforts and contributions have been invaluable and key to the plan's content and eventual completion.



Besides the members of the UCCCI, a number of other organizations and individuals contributed to the UCCCI's success. These included the Centers for Disease Control and Prevention and the Battelle Centers for Public Health Research and Evaluation. Their support and technical assistance were critical in helping to initiate this project. Additionally, consultants from Strategic Health Concepts helped establish and guide the process by which the plan was developed and eventually completed.

Utah is one of six model states engaged in comprehensive cancer control planning. Other participating states include Arkansas, Illinois, Kentucky, Kansas and Maine. Their prior experiences provided the blueprint that contributed to the successful development of Utah's plan. In addition, Michigan, North Carolina, Colorado, Texas, Massachusetts, and the Northwest Portland Area Indian Health Board were also helpful in sharing the knowledge they have gained in the process of developing comprehensive cancer control plans.

The process of developing a plan in itself has been a very beneficial and rewarding experience. Through this effort, many organizations and individuals have developed positive relationships and are working together to coordinate efforts and expand the work of cancer prevention and control in Utah.

This plan acknowledges all those who have been touched by cancer and all those who are working toward reducing its burden on the citizens of Utah.

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FOREWORD

Many cancer-related programs are categorical in nature; that is, they are built around specific cancer sites (e.g. breast, prostate, lung, etc.) and risk factors (e.g. poor nutrition, use of tobacco, etc.). As a result, there is often lack of coordination and collaboration among these programs, efforts are duplicated, and opportunities for cancer prevention and control may be missed.

Recognizing this, the Centers for Disease Control and Prevention developed the following definition in an effort to help organizations address cancer on a comprehensive scale. Comprehensive cancer control is an integrated and coordinated approach to reducing cancer incidence, morbidity, and mortality through prevention, early detection, treatment, rehabilitation and palliation.

The UCCCI seeks to bring together organizations (See Appendix A) in a collaboration to assess cancer needs, prioritize these needs, and develop a plan to address them in a manner that supports the definition of comprehensive cancer control. Finally, the UCCCI will continue its work to implement and maintain the plan.

This plan provides a set of specific action steps to be conducted over the next five years. These efforts are considered high priority activities that encompass the spectrum of cancer care including Prevention, Early Detection, Treatment and Quality of Life.

Cancer places a significant burden on the lives of many Utahns. The mission of the UCCCI is to reduce cancer incidence and mortality in Utah through collaborative efforts that provide services and programs directed toward comprehensive cancer prevention and control. It is the hope of the UCCCI that through a collaborative effort, the plan's goals and objectives will be achieved, and the burden of cancer among Utahns will be reduced.

HISTORY OF THE INITIATIVE



A strategic planning process was conducted by the Division of Cancer Prevention and Control (DCPC) at the Centers for Disease Control and Prevention (CDC) during 1994 and 1995. This process revealed a need for a comprehensive approach to prevention, early detection, and treatment for state, territorial, and Indian Health Service cancer programs. As a result of this process, DCPC began to design a framework to assist public health agencies in the development of comprehensive cancer control plans.

The Batelle Centers for Public Health Research and Evaluation, an organization assigned by DCPC to guide states in comprehensive planning, conducted a site visit to Utah in May 1998. Information regarding Utah's data, community, interorganizational resources, previous planning experience, barriers and facilitators was collected. Shortly thereafter, Utah was selected as one of six model states for comprehensive cancer control planning. After being selected as a model state, the Utah Department of Health (Department) established the Utah Comprehensive Cancer Control Initiative (UCCCI). A coordinator was assigned to administer and oversee the UCCCI and representatives from the Department's Bureau of Health Promotion assisted with the planning process.

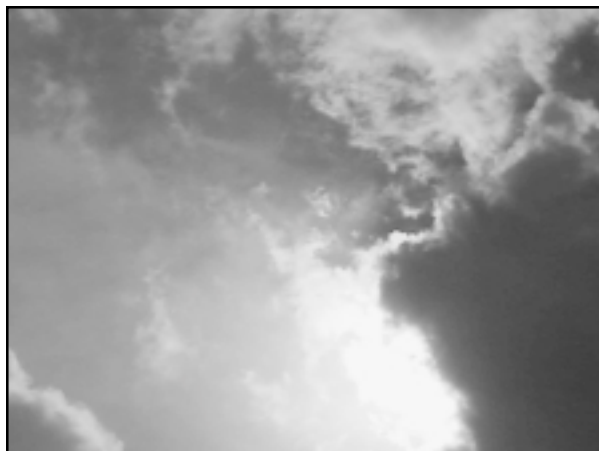
As a first step to establishing a multi-organizational committee, the Department administered a survey (see Appendix B) to hospital administrators, physicians, staff from local and state health departments, nonprofit groups, educational institutions, and managed care organizations with a mission related to cancer control. This survey was conducted to assess the interest of stakeholders in participating in the development of a comprehensive plan for Utah, to develop an inventory of existing resources, and perceived needs, strengths, and weaknesses related to cancer prevention and control.

The results of the survey revealed a great deal of support for comprehensive cancer planning in Utah. Most respondents (84%) perceived a need for a comprehensive plan, while 75% stated they would like to participate in the development of such a plan. Respondents identified healthy life style practices as Utah's major strength in cancer control, while lack of education and preventive services were identified as Utah's major weaknesses. Respondents expected to benefit from the UCCCI through improved access to data, prevention and early detection efforts, and networking opportunities. Respondents who expressed willingness to participate in the development of the plan were contacted and invited to join the UCCCI.

The first UCCCI meeting was held on May 2, 2000 at the Little America Hotel in Salt Lake City. Following this initial meeting, a total of six large and twelve subgroup meetings were held between July 2000 and December 2001. Tom Kean of *Strategic Health Concepts* was hired to facilitate this process. Organizations involved in the UCCCI hosted the meetings.

During early UCCCI meetings, an infrastructure was proposed and adopted. The roles of the Department, the core implementation team, and the small work groups were defined. Four work group committees were established to address prevention, early detection, treatment, and quality of life. A decision-making process was presented and adopted. The work groups developed problem statements, goals and objectives, and identified strategies to achieve them. In the September 2001 meeting, the UCCCI identified issues that were common among all the Prevention, Early Detection, Treatment and Quality of Life goals and objectives. Three common themes emerged that were focused around consumer and patient issues, the need for data and improved research, and methods to improve care delivery systems and infrastructure. As a result, three new work groups, Consumer/Patient, Health Care Provider, and Data were formed. By addressing crosscutting issues, the UCCCI is better positioned to achieve the comprehensive goals of the plan. Future meetings will focus on implementation, including prioritization of strategies. Using the plan as a blueprint, organizations and individuals that comprise the UCCCI will initiate implementation of strategies that will ultimately reduce the burden of cancer in Utah and guide current and future efforts in the area of comprehensive cancer control.

THE BURDEN OF CANCER IN UTAH



INCIDENCE

Cancer incidence rates increased between 1980 and 1998 in both the U.S. and Utah. In the U.S., the cancer incidence rate increased by 14%, from a rate of 345.9/100,000 in 1980 to 395.3/100,000 in 1998. In Utah, the cancer incidence rate increased by nearly 17%, from 289.3/100,000 in 1980 to 339.5/100,000 in 1998.^{1,2}

Trends in cancer incidence vary by site. For example, lung cancer incidence increased in

both the U.S. and Utah between 1980 and 1998, making it the leading cause of cancer death for both men and women. The incidence of prostate cancer and melanoma also increased in the U.S. and Utah between 1980 and 1998. In contrast, the incidence of cervical cancer declined in both the U.S. and Utah between 1980 and 1998.^{1,2}

For most cancers, the incidence rate for Utah is lower than for the U.S. However, the incidence of melanoma is higher in Utah than in the U.S., with a rate of 17.3/100,000 in Utah compared with a U.S. rate of 14.3/100,000 in 1998. The incidence of prostate cancer is higher in Utah as well, with a rate of 141.6/100,000 in 1998 compared with a U.S. rate of 137.3/100,000.^{1,2}

Between 1995 and 1999, the overall cancer incidence rate was higher for men than for women, with rates of 306.7/100,000 and 269.8/100,000 respectively. Higher incidence rates among men compared to women were also found for lung cancer (27/100,000 vs. 16.9/100,000), melanoma (17.2/100,000 vs. 13.3/100,000), and colorectal cancer (30.8/100,000 vs. 28.7/100,000).^{1,2}

MORTALITY

In the U.S. in 1998, there were 541,532 deaths due to cancer, making it the second leading cause of death for Americans. Between 1980 and 1998, mortality due to cancer decreased by almost 4% in the U.S. from a rate of 168/100,000 to 161.5/100,000.³ Cancer is also the second leading cause of death in Utah. In Utah between 1980 and 1998, more than 34,000 deaths occurred due to cancer, and the cancer mortality rate increased slightly from a rate of 122.2/100,000 to 125.4/100,000.⁴

Trends in cancer mortality vary by site. For example, mortality due to lung cancer has increased in Utah and the U.S. since 1980. In contrast, deaths due to colorectal cancer declined in the U.S. and Utah between 1980 and 1998. While mortality due to breast cancer has decreased slightly in the U.S. from a rate of 14.8/100,000 in 1980 to 12.6/100,000 in 1998, Utah's breast cancer mortality rate remained nearly the same. However, since 1980, the breast cancer mortality rate for women in Utah has been

consistently lower than the rate for the U.S. In fact, between 1994 and 1998, Utah had the second lowest breast cancer mortality rate in the nation (20.6/100,00 compared to the U.S. rate of 24.2/100,000).^{2, 3}

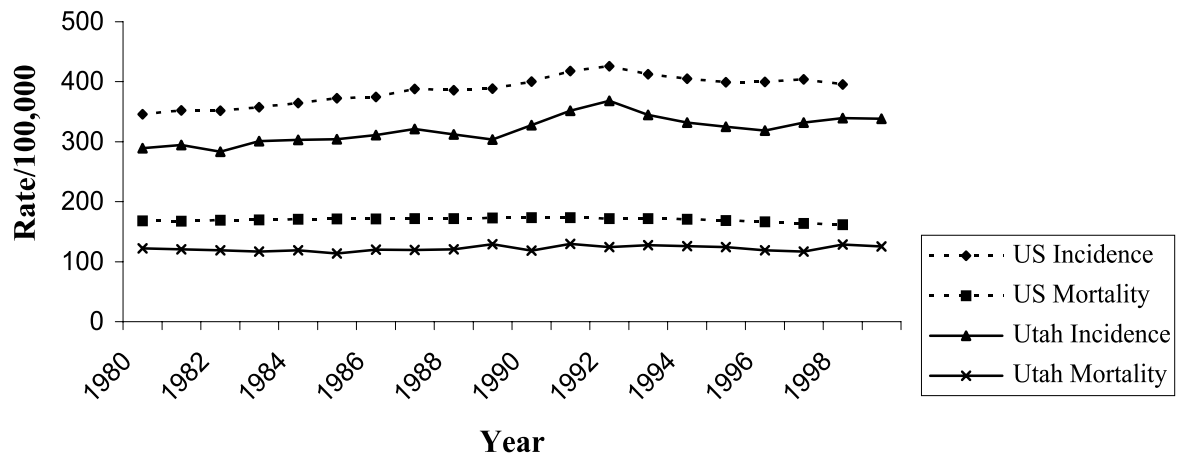
For most cancers, Utah's mortality rates are lower than the U.S. rates. Mortality due to cervical cancer in Utah is very low, with a 1998 rate of 0.9/100,000 compared to a U.S. rate of 2.5/100,000. However, mortality due to melanoma is higher in Utah with a rate of 3.1/100,00 compared to U.S. rate of 2.3/100,000 in 1998.^{2, 3}

Between 1995 and 1999, the mortality rate for all cancers in Utah was higher for men than for women, with rates of 115/100,000 and 100.2/100,000 respectively. Higher mortality rates among men compared to women were also found for lung cancer (22.7/100,000 vs 13.6/100,000) and melanoma (3/100,000 vs 1.7/100,000). However, for these same years, Utah women had a slightly higher mortality rate due to colorectal cancer than men (11.8/100,000 vs. 11.3/100,000).³

COST

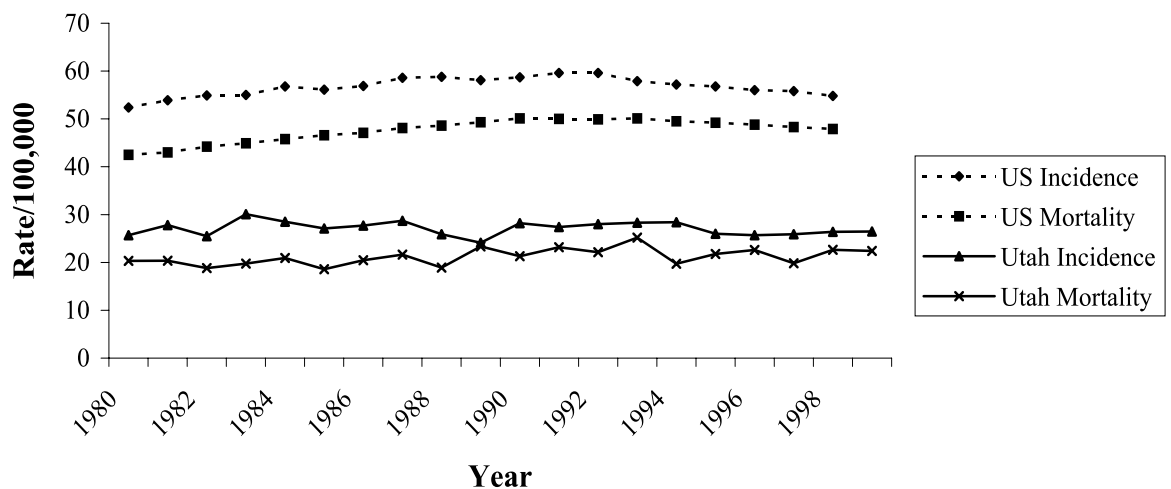
During 2000, cancer cost the U.S. approximately \$180.2 billion. Of this total an estimated \$60 billion was spent for direct medical costs, \$15 billion for lost productivity due to illness, and \$105.2 billion for lost productivity due to premature death.⁵ In Utah during 1998, more than 5,000 hospital discharges for cancer occurred. Over \$85 million was spent on hospitalizations for cancer in Utah during 1998, at a rate of more than \$230,000 per day.⁶

**Figure 1. Cancer (All Sites) Incidence and Mortality Rates*,
Utah and United States 1980-1999**



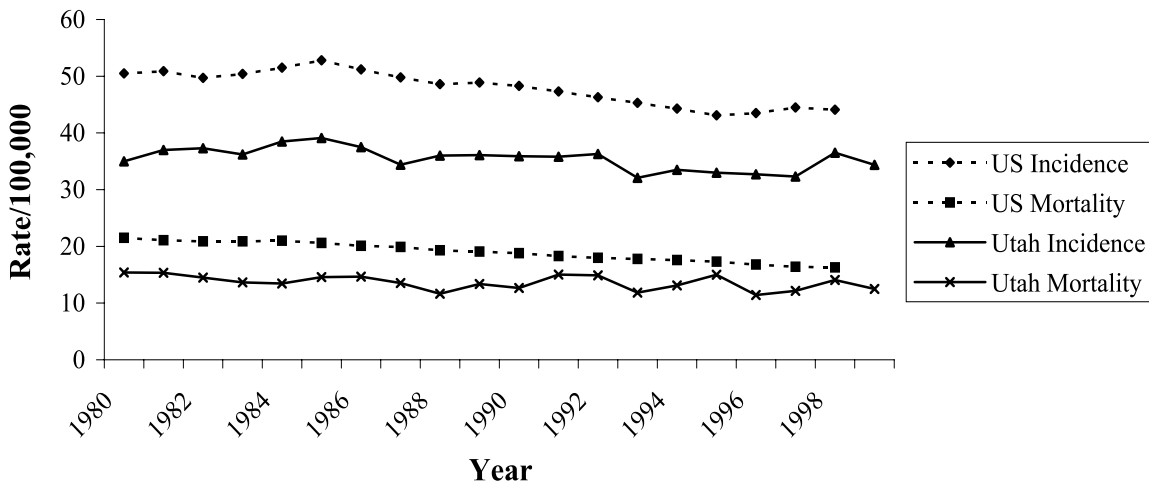
Source: Utah Cancer Registry; Utah Department of Health, Office of Vital Records and Statistics; SEER
 *Rates are age adjusted to the 1970 U.S. standard population

**Figure 2. Lung Cancer Incidence and Mortality Rates*,
Utah and United States 1980-1999**



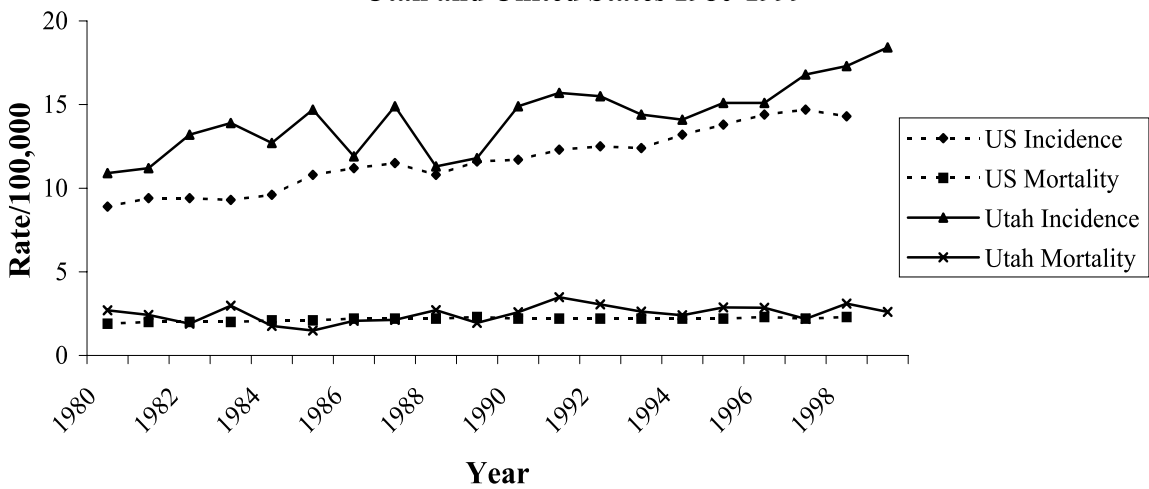
Source: Utah Cancer Registry; Utah Department of Health, Office of Vital Records and Statistics; SEER
 *Rates are age adjusted to the 1970 U.S. standard population

**Figure 3. Colorectal Cancer Incidence and Mortality Rates,
Utah and United States 1980-1999**



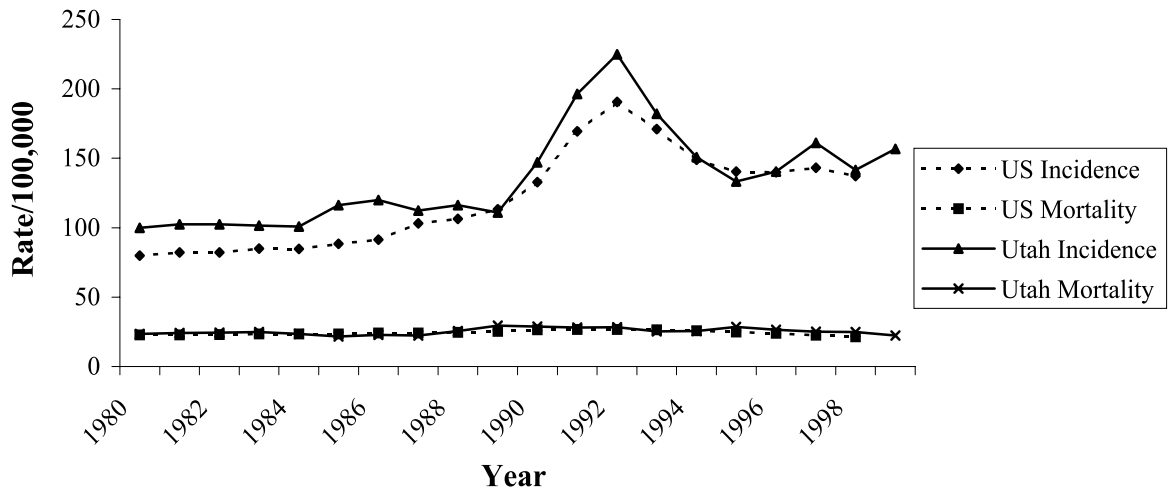
Source: Utah Cancer Registry; Utah Department of Health, Office of Vital Records and Statistics; SEER
 *Rates are age adjusted to the 1970 U.S. standard population

**Figure 4. Melanoma Cancer Incidence and Mortality Rates*,
Utah and United States 1980-1999**



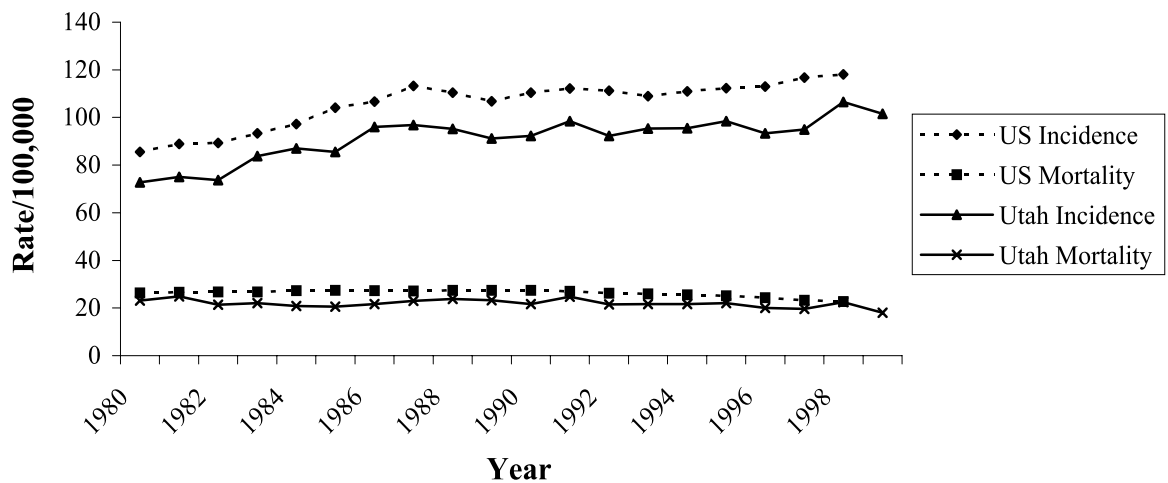
Source: Utah Cancer Registry; Utah Department of Health, Office of Vital Records and Statistics; SEER
 *Rates are age adjusted to the 1970 U.S. standard population

Figure 5. Prostate Cancer Incidence and Mortality Rates* Among Men, Utah and United States 1980-1999



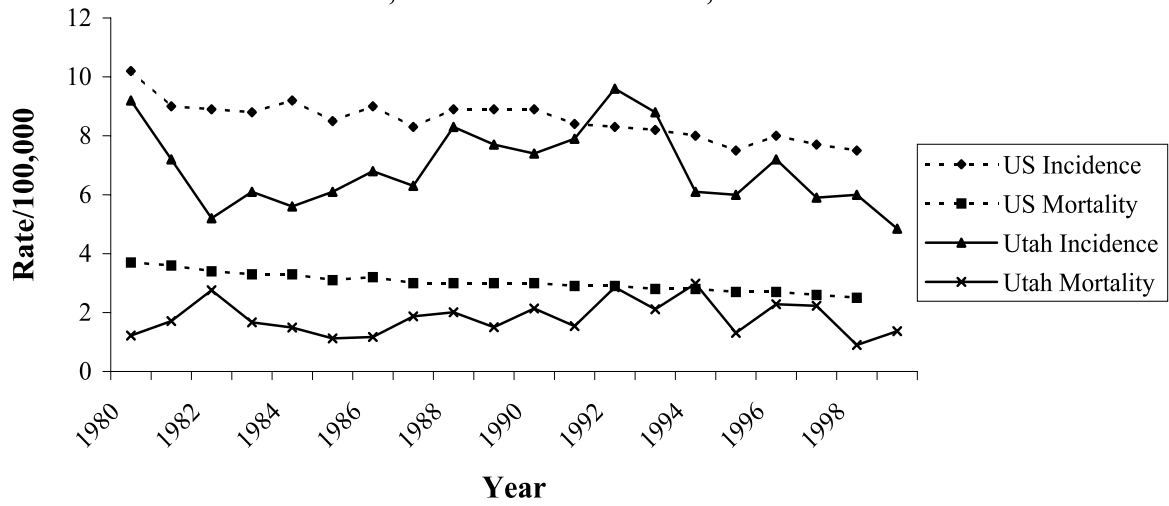
Source: Utah Cancer Registry; Utah Department of Health, Office of Vital Records and Statistics; SEER
 *Rates are age adjusted to the 1970 U.S. standard population

Figure 6. Breast Cancer Incidence and Mortality Among Women, Utah and United States 1980-1999



Source: Utah Cancer Registry; Utah Department of Health, Office of Vital Records and Statistics; SEER
 *Rates are age adjusted to the 1970 U.S. standard population

Figure 7. Cervical Cancer Incidence and Mortality Rates* Among Women, Utah and United States, 1980-1999



Source: Utah Cancer Registry; Utah Department of Health, Office of Vital Records and Statistics; SEER

*Rates are age adjusted to the 1970 U.S. standard population

PRIMARY PREVENTION



Primary prevention, or preventing the occurrence of cancer, is essential to reducing the cancer burden for Utahns. Primary prevention efforts often focus on reducing the occurrence of cancer risk factors in a population. Primary prevention strategies to reduce or prevent tobacco use, obesity, improper nutrition, physical inactivity, and sun exposure for Utah's population are needed to reduce the occurrence of cancer in Utah. Primary prevention goals and objectives have been developed for these priority areas and are presented below.

COLORECTAL CANCER

Research suggests that a diet of five or more servings of fruits or vegetables each day may be associated with reduced risk for colorectal cancer.⁷ In Utah during 2000, only 21% of adults reported consuming at least five servings of fruits and vegetables daily.⁸ In 1999, only 26% of high school students reported consuming at least five servings of fruits and vegetables daily.⁹ Lack of physical activity may also be a risk factor for colorectal cancer.⁷ In Utah during 2000, 26% of adults reported engaging in physical activity for 30 minutes per day at least five days per week.⁸ Among high school students, 31% reported vigorous physical activity at least three times per week in 1999.⁹ Finally, obesity may be a risk factor for colorectal cancer.⁷ In Utah during 2000, 54% of adults reported being overweight, based on Body Mass Index of greater than or equal to 25.⁸ Alarming, the proportion of adults who are obese has increased by nearly 26% since 1990 in the U.S.⁸

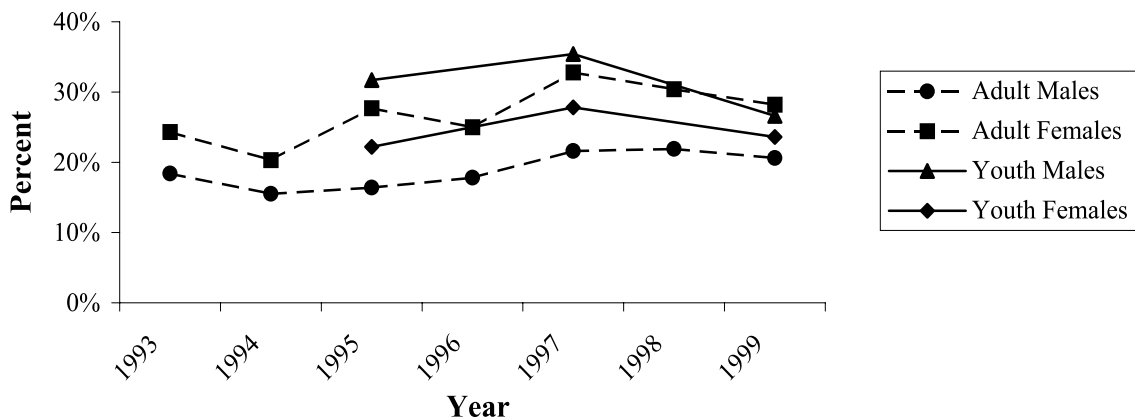
Goal 1: Reduce the incidence of colorectal and other cancers through healthful eating habits and physical activity.

Objective 1.1: Increase the proportion of adults who eat five servings of fruits and vegetables per day to at least 30% by 2005.

Strategies :

1. Support A Healthier You 2002 Nutrition Program for 5 a Day.
2. Continue to conduct at least 3 major media campaigns or events publicizing 5 a Day.
3. Analyze existing 5 a Day data, present it to the Cardiovascular Health Alliance Nutrition Work Group, and develop a 3-year state plan.
4. Establish a formative research base for knowledge, attitudes, behaviors and barriers to good nutrition choices in seniors aged 55-70; minority populations; and five priority health districts.

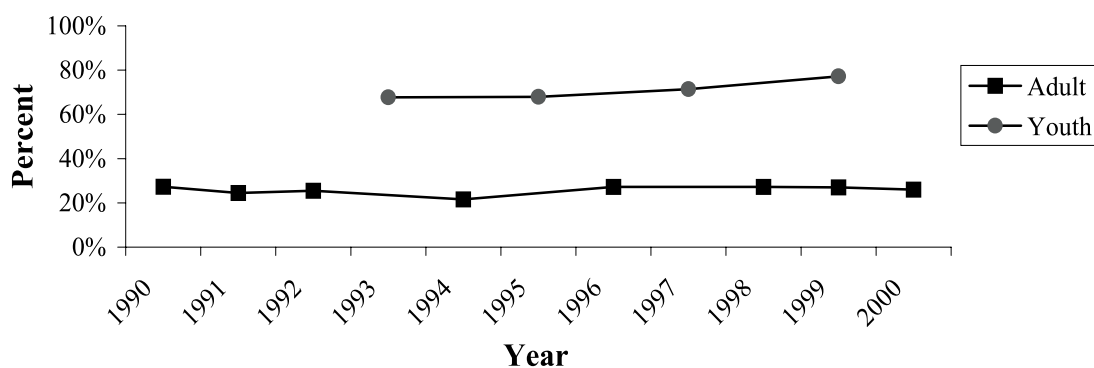
Figure 1: The Percentage of Adults and Youth* Who Reported Consuming 5 a Day By Gender, Utah 1993-2000



*Data for youth are available for 1995, 1997, and 1999 only. In 1995, four fruit and vegetable questions were asked for the day preceding the survey only. In 1999, six fruit and vegetable questions were asked regarding the past 7 days.

Source: Utah Behavioral Risk Factor Surveillance System and Youth Risk Behavior Survey

Engaging in Physical Activity, Utah 1990-2000



*Physical activity was defined as at least 30 minutes per day 5 or more days/week

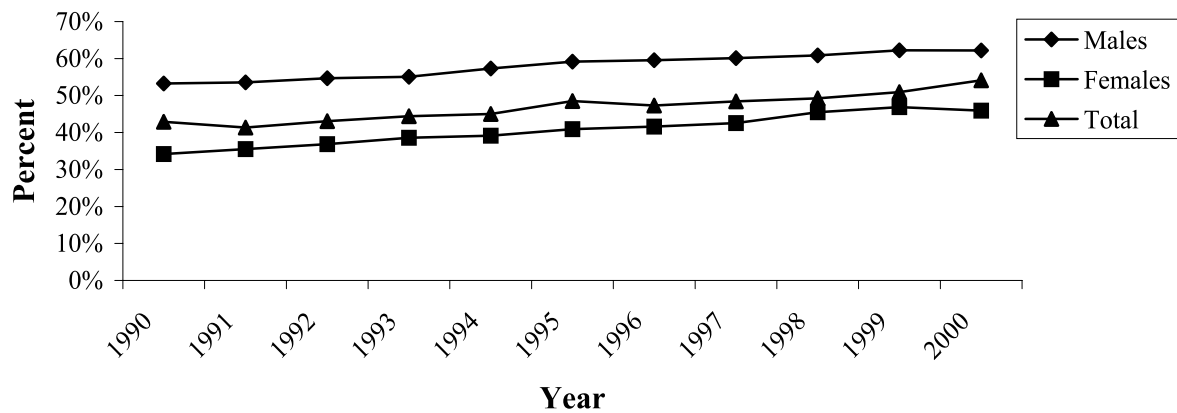
**Physical activity was defined as vigorous activity 3 or more days/week

Data for youth are only available for the years 1993, 1995, 1997, & 1999

Data for adults are only available for the years 1990-1992, 1994, 1996, & 1998-2000

Source: Utah Behavioral Risk Factor Surveillance System and Youth Risk Behavior Survey

Figure 3: The Percentage of Adults Classified as Overweight* or Obese by Gender, Utah 1990-2000**



*Body mass index of 25-29

**Body mass index of 30 or greater

Source: Utah Behavioral Risk Assessment Surveillance System

Objective 1.2: Increase the proportion of young people who eat five servings of fruits and vegetables per day to at least 35% by 2005.

Strategies:

1. Continue to offer tours of grocery produce departments to 3rd graders.
2. Support the Gold Medal School Incentive Project, which promotes physical activity, healthy nutrition choices, and tobacco abstinence, in at least 20 schools.
3. Provide training for middle school food services in providing Gold Medal meals for students.

Objective 1.3: Increase the proportion of adults that engage regularly, preferably daily, in sustained physical activity for at least 30 minutes to 30% or more by 2005.

Strategies:

1. Collaborate with the Utah Council on Health and Physical Fitness to complete an inventory of worksite policy and environmental strategies that promote physical activity.
2. Support “A Healthier You 2002” in establishing Legacy Gold Medal Miles in at least 30 communities.
3. Conduct an inventory of policies and environmental strategies that promote physical activity in at least 12 communities.

Objective 1.4: Increase the proportion of young people that engage regularly, preferably daily, in sustained physical activity for at least 30 minutes to 35% or more by 2005.

Strategies:

1. Promote “Walk to School Day” activities in at least 100 schools.
2. Support the Gold Medal School Incentive Project, which promotes physical activity, healthy nutrition choices, and tobacco abstinence, in at least 20 schools.

Objective 1.5: Decrease the proportion of adults who are overweight to no more than 30% by 2005.

Strategies:

See strategies for objectives 1.1 and 1.3.

TOBACCO

Tobacco use is a risk factor for lung, mouth, throat, larynx, bladder, and many other types of cancer.⁷ Environmental tobacco smoke (ETS) may be associated with cancer as well as other health problems.⁷ In Utah during 2000, nearly 13% of adults reported smoking.⁸ Among Utah youth, 12% reported current smoking, 39% reported having tried smoking, and 4% of males reported current smokeless tobacco use in 1999.⁹ For those who use tobacco, quitting may be associated with a decreased risk for cancer. Research shows that physician advice to quit smoking is one of the most effective smoking cessation interventions, yet only half of smokers have been urged by their physicians to quit smoking.¹⁰

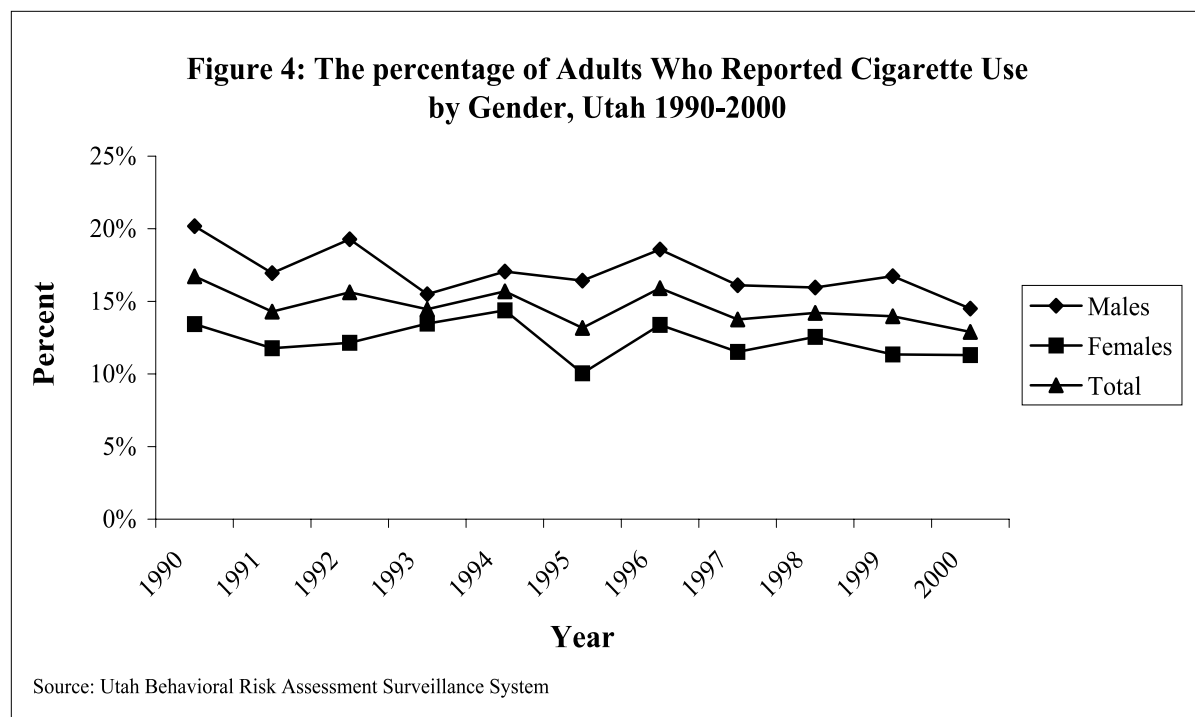
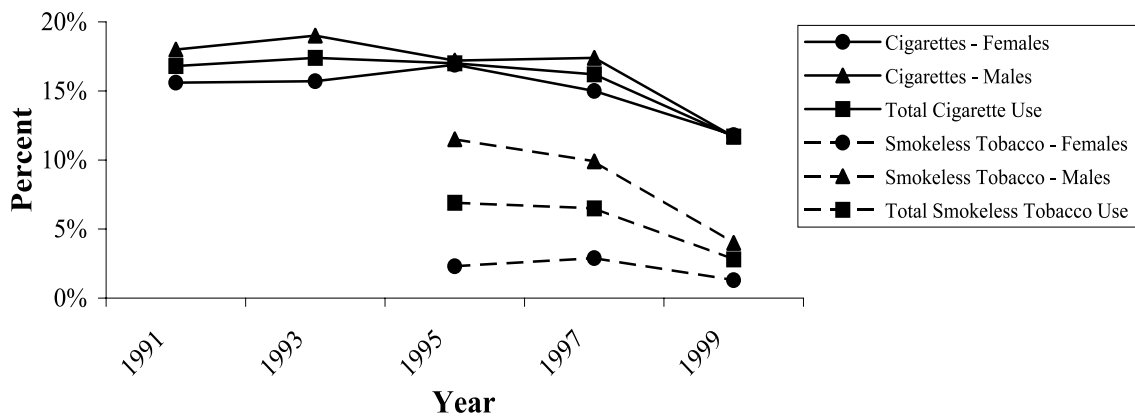


Figure 5: The Percentage of High School Students Who Reported Current* Cigarette and Smokeless Tobacco use by Gender, Utah 1991-1999**



*Smoked at least once in the past 30 days

**Used smokeless tobacco or snuff at least once in the past 30 days

Data are available for odd years only

Source: Utah Youth Risk Behavior Survey

Goal 2: Reduce the initiation of tobacco use, increase tobacco cessation, and reduce exposure to ETS.

Objective 2.1: Reduce the proportion of Utah adults aged 18 and older who smoke cigarettes to no more than 10% by 2005. Reduce the proportion of Utah adult males who use smokeless tobacco to no more than 2%.

Strategies:

1. Support legislation to increase the tobacco excise tax and appropriate dollars from the Master Settlement Agreement to programs for tobacco prevention and cessation.
2. Implement community-based programs statewide that engage local organizations, schools, youth, parents, enforcement officials, community and business leaders, and health care providers in tobacco prevention and control efforts.
3. Promote government and voluntary policies to promote clean indoor air and provide insurance coverage for tobacco cessation.
4. Continue to implement a research-based media campaign using TV, radio, and print materials to counter pro-tobacco influences and promote smoking cessation.
5. Increase the availability of smoking cessation programs, including those for high risk and disparate populations.

Objective 2.2: Reduce the proportion of Utah youth that smoke cigarettes to no more than 9% by 2005. Reduce the proportion of Utah youth that have tried cigarette smoking to no more than 35% by 2005. Reduce the proportion of Utah male youth that use smokeless tobacco to no more than 2%.

Strategies:

1. Implement community-based tobacco prevention and control programs statewide that engage youth in developing and implementing tobacco control interventions. Programs should include youth advocacy and parental involvement.
2. Support schools in the implementation of *Centers for Disease Control and Prevention's School Guidelines*, including the tobacco policy development and enforcement, student instruction regarding short and long term effects of tobacco use, prevention education in grades 5–12, teacher training, parental involvement, and cessation support for students and school staff who use tobacco.
3. Provide accessible, affordable, and proven cessation programs for youth focusing on high risk and disparate populations.
4. Continue to implement a research-based media campaign using TV, radio, and print materials to counter pro-tobacco influences and prevent tobacco use by youth.
5. Promote government and voluntary policies to restrict youth access to tobacco products.

Objective 2.3: Eliminate involuntary exposure to ETS for all Utahns.

Strategies:

1. Promote state and local policies that restrict smoking in public places.
2. Increase enforcement of and monitor compliance with existing indoor clean air laws.
3. Educate Utah businesses regarding the Utah Indoor Clean Air Act.
4. Continue to implement a research-based media campaign using TV, radio, and print materials to eliminate exposure to ETS.
5. Develop and distribute ETS educational kits for homes, workplaces, and cars.
6. Provide training and printed materials to encourage health care providers to inform and counsel their patients about the negative health effects of ETS.

Objective 2.4: Increase the proportion of patients who receive advice to quit smoking each year from a health care provider.

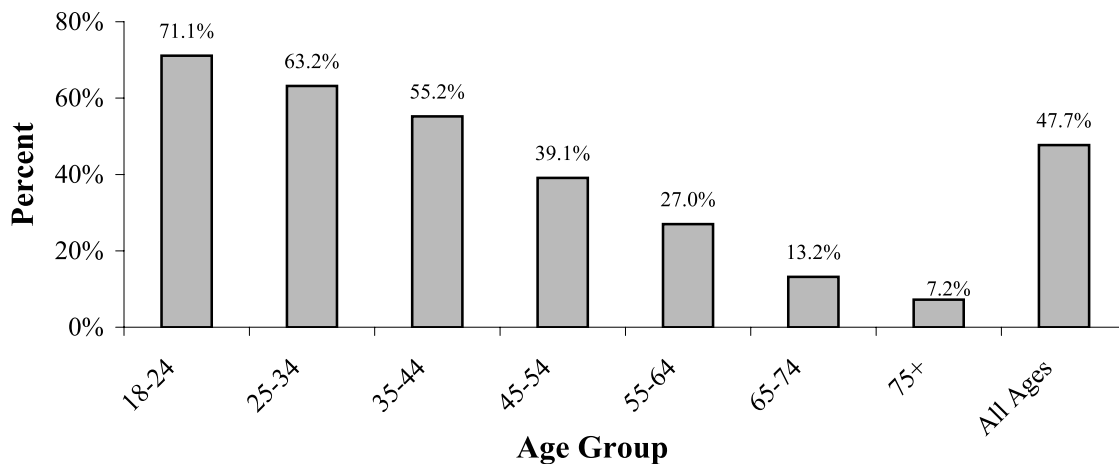
Strategies:

1. Train health care providers to assist their patients with smoking cessation.
2. Plan and implement a program to encourage health care providers to follow *The Public Health Service Clinical Practice Guidelines* with regard to tobacco use.
3. Provide resources to health care providers to assist in implementing these guidelines, such as the Healthier You 2002 prescription pads.

SKIN CANCER

Exposure to ultraviolet (UV) light from sun, tanning booths, and sunlamps, may increase the risk of non-melanoma skin cancer. In addition, frequent sunburn may be a risk factor for melanoma. Sun protection measures, including avoiding the sun between 11:00 A.M. and 3:00 P.M., wearing a hat and long sleeved shirt, and using sunscreen may be protective against skin cancer.⁷ In Utah during 2000, nearly 64% of adults reported usually taking measures to protect their skin

Figure 6: The Percentage of Adults Who Reported Acquiring a Sunburn in the Past 12 Months by Age Group, Utah 2000



Source: Utah Behavioral Risk Factor Surveillance System

when exposed to the sun for more than one hour and nearly 48% of adults reported obtaining a sunburn in the past 12 months.⁸

Goal 3: Reduce the incidence of skin cancer in Utah.

Objective 3.1: Decrease the proportion of adults who acquired a sunburn during the previous year to no more than 30% by 2005.

Strategies:

1. Investigate potential data sources to determine the proportion of people who protect themselves from UV rays.
2. Research the characteristics of those who are not taking steps to protect their skin.
3. Educate the public on sun protection, including the proper use of sunscreen and protective clothing.
4. Discourage the use of tanning beds.
5. Establish a committee to catalogue resources and programs related to sun protection.
6. Plan, implement, and evaluate a pilot program based on social marketing principles.

Objective 3.2: Decrease the proportion of young people who acquired a sunburn in the previous year to no more than 30% by 2005.

Strategies:

1. Investigate potential data sources to determine the proportion of young people who acquired a sunburn in the past 12 months.
2. Research the characteristics of those who are not taking steps to protect their skin.

3. Educate parents and child care providers on sun protection for their children, including the proper use of sunscreen and protective clothing.
4. Discourage the use of tanning beds by teens.
5. Establish a committee to catalogue resources and existing programs related to adolescents and sun protection.
6. Plan, implement, and evaluate a pilot program for youth based on social marketing principles.

Objective 3.3: Obtain accurate rates of the occurrence of basal and squamous cell skin cancers in Utah.

Strategy:

1. Work with the Utah Cancer Registry to determine a method to collect information on the occurrence of basal and squamous cell skin cancers in Utah.

ALTERNATIVE THERAPY

The use of certain alternative medicines for cancer prevention, including vitamin supplements and natural remedies, may result in adverse health effects or wasted resources for Utahns. Primary prevention to educate health consumers about the informed use of these therapies and to ensure the safety of such therapies is needed.

Goal 4: *Promote the safe use of alternative therapies, including vitamin supplements and natural remedies.*

Objective 4.1: Collaborate with naturopaths and other interested persons to increase the safety of alternative therapies that are available to the public.

Strategies:

1. Advocate for state legislation to allow regulation of vitamin supplements and herbal remedies sold in stores, including labeling, drug and food interactions, and contraindications.
2. Advocate for funding to support clinical trials to investigate the safety and effectiveness of alternative therapies in the prevention and treatment of cancer.
3. Provide public education about the content of herbal remedies, including the development of an education message and channel, based on social marketing theory, about myths and facts regarding the use of vitamin supplements and herbal remedies for cancer prevention and control.

CANCER PREVENTION RESEARCH

Knowledge about primary prevention of cancer is currently limited. Cancer prevention trials are being conducted to increase this body of knowledge. According to Utah researchers, enrollment in some cancer prevention trials has been relatively low. Strategies are needed to increase enrollment in cancer prevention studies in Utah.

Goal 5: *Increase enrollment in cancer prevention research being conducted in Utah.*

Objective 5.1: Encourage referrals to cancer prevention trials by primary care and other health care providers.

Strategies:

1. Provide information about cancer prevention trials to newsletters, list serves, professional conferences, mailings, and other forums frequented by health care providers.
2. Encourage investigators to use knowledgeable and enthusiastic spokespersons for cancer prevention trials.

Objective 5.2: Recruit participants for cancer prevention trials, including representatives of diverse age, racial, and ethnic groups.

Strategies:

1. Identify and work with media partners to educate the public about the importance of cancer prevention research and specific cancer prevention studies in Utah.
2. Use media channels to recruit study subjects.

EARLY DETECTION

Early detection, or identifying a disease at an early stage, is critical to effective treatment. Early detection is considered to be secondary prevention in that it reduces morbidity and mortality. Early detection can be implemented by screening an entire population or by screening only those at high risk for a disease. For more expensive or invasive screening tests, it is often more cost effective to screen only those at high risk for a disease.¹¹ Early detection is frequently applied to the identification of cancer. For example, mammograms and Papanicolaou (Pap) smears are routinely used to screen for breast and cervical cancers.



PROSTATE CANCER

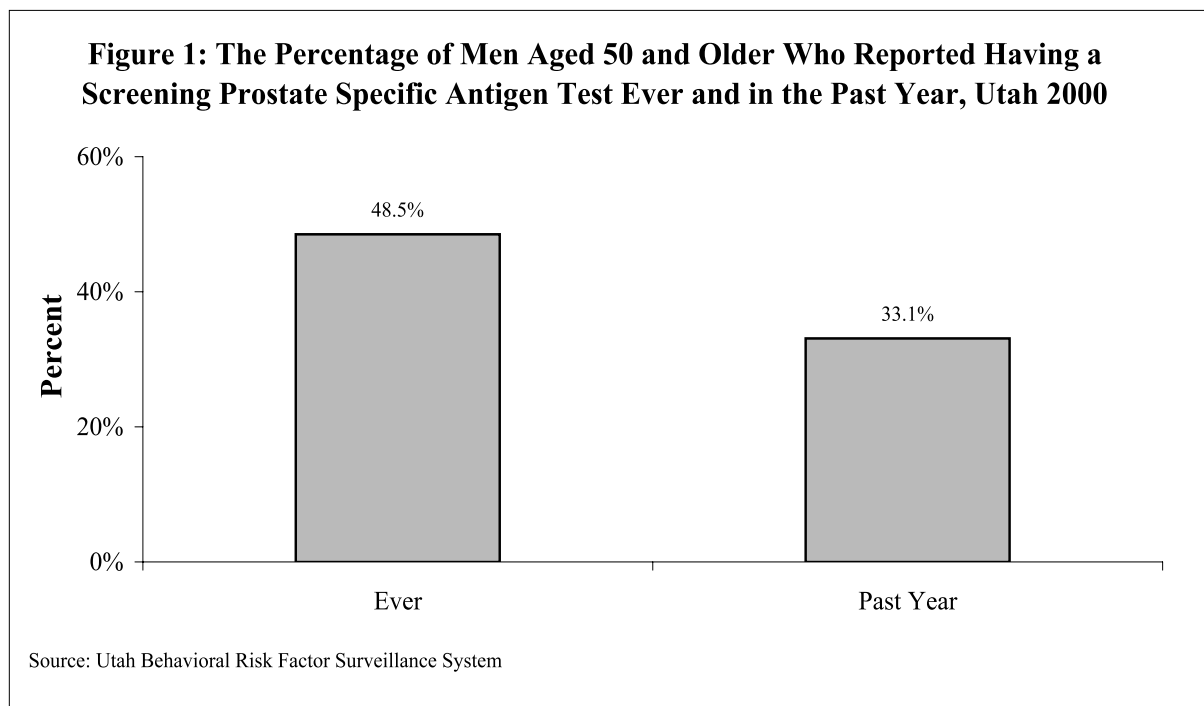
Prostate cancer is the second leading cause of cancer death for men in Utah as well as the U.S.^{4,12} African-American men and men aged 50 or older are at an increased risk for prostate cancer.¹² In Utah between 1989 and 1999 nearly 13,000 new cases of prostate cancer were diagnosed.¹ During 1999, 1,247 new cases of prostate cancer were diagnosed and 189 deaths occurred due to this disease in Utah.^{1,4} The incidence of prostate cancer is higher in Utah than the U.S., in 1998 the prostate cancer incidence rate was 141.6 per 100,000 men in Utah while in the U.S. only 137.3 out of every 100,000 men were diagnosed with prostate cancer.^{1,2} Two tests are commonly used to screen for prostate cancer, prostate specific antigen (PSA) and digital rectal exam (DRE). These tests may be more effective when conducted together.¹² Screening for prostate cancer is controversial because it is not clear that early detection of tumors results in reduced mortality.¹² However, the American Cancer Society recommends health care providers offer the PSA and DRE screening tests annually to men aged 50 and older.¹³ In Utah during 2000, 33% of men aged 50 and older reported having a PSA test in the past year.⁸

Goal 1: Promote, increase, and optimize the appropriate utilization of prostate cancer screening and follow-up services.

Objective 1.1: Increase prostate cancer screening and follow-up among high-risk populations.

Strategies:

1. Educate the public by disseminating American Cancer Society recommendations.
2. Support provider use of both PSA and DRE when screening for prostate cancer.
3. Incorporate systems change for appropriate follow-up care.
4. Increase community support for informed prostate cancer screening among high risk populations.



Objective 1.2: Increase provider dialogue with men aged 50 and older regarding prostate cancer screening.

Strategy:

1. Give talking points to providers for use when discussing prostate cancer screening with patients.

CERVICAL CANCER

Between 1989 and 1999, more than 700 new cases of cervical cancer were diagnosed in Utah.¹ In 1999, there were 53 new cases of cervical cancer diagnosed and 15 deaths due to this disease in Utah.^{1,4} Cervical cancer screening rates are relatively high in Utah. During 2000, 80% of women aged 18 or older reported that they had a Pap test in the past three years.⁸ However, lower rates were reported among certain populations. Only 72% of women without health insurance coverage, 76% of Asian/Pacific Islander women, and 70% of women aged 65 and older reported having had a Pap test in the past three years.⁸

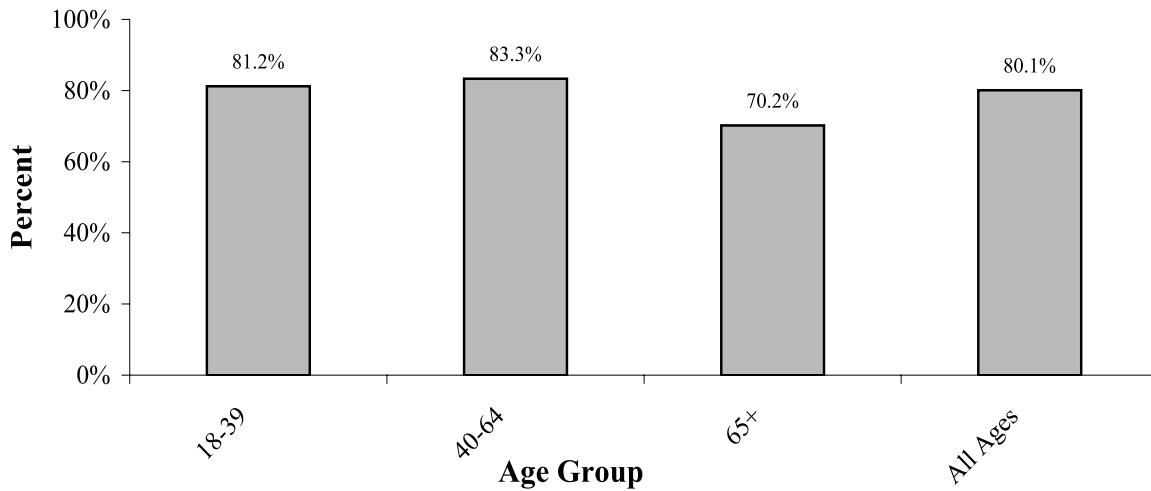
Goal 2: Promote, increase, and optimize the appropriate utilization of cervical cancer screening and follow-up services.

Objective 2.1: Increase cervical cancer screening rates in populations with the lowest screening rates, such as Asian/Pacific Islanders, the elderly, and refugees.

Strategies:

1. Identify marketing channels appropriate to promoting cervical cancer screening for the intended populations.
2. Work with primary care provider office staff to integrate cervical cancer screening into the patients' overall preventive health care.

Figure 2: The Percentage of Women Aged 18 and Older Who Reported Having a Pap Test in the Past Three Years by Age Group, Utah 1998-2000



Source: Utah Behavioral Risk Factor Surveillance System

TESTICULAR CANCER

Testicular cancer is rare, with only 619 cases diagnosed in Utah between 1989 and 1999.¹ Mortality due to testicular cancer is low because treatment is often successful.⁷ In 1999, there were 47 new cases of testicular cancer diagnosed and fewer than five deaths due to this disease in Utah.^{1,4} Although testicular cancer is rare, it is the most common form of cancer in White men 20 to 34 years of age. Risk factors include White race, family history, previous testicular tumor, cryptorchidism, gonadal dysgenesis, and Klinefelter's syndrome.^{7,12,14} According to the National Cancer Institute, there is not enough evidence to suggest that regular screening for this cancer would save lives.⁷ However, the American Cancer Society recommends that testicular cancer screening exams be performed during regular physical exams and that patients discuss the need for regular self-exam with their health care providers.¹⁴

Goal 3: Promote, increase and optimize the appropriate utilization of regular testicular cancer screening and follow-up services.

Objective 3.1: Increase rates of testicular self-exam and testicular exams provided by health care providers.

Strategies:

1. Educate the public about testicular screening recommendations.
2. Educate health care providers about testicular screening recommendations.
3. Incorporate testicular screening exams into required physicals for athletic, missions, armed service, and other health exams.

4. Disseminate testicular cancer screening recommendations to providers at emergency facilities, outpatient clinics, and other facilities commonly utilized by the intended populations.
5. Include information about testicular cancer screenings in health curricula taught in public schools and work with health teachers and coaches to ensure that they are prepared to teach the subject matter.

SKIN CANCER

There are three types of skin cancer: basal cell, squamous cell, and malignant melanoma.⁷ Basal and squamous cell skin cancers are highly treatable, but can be deforming or deadly when treatment is delayed. Malignant melanoma, the rarest of the three types, is responsible for most skin cancer deaths.⁷ In Utah nearly 3,000 new cases of malignant melanoma were diagnosed between 1989 and 1999.¹ In 1999, there were 368 new cases of malignant melanoma diagnosed and 49 deaths due to this disease.^{1,4} Information about the incidence of and deaths due to basal and squamous cell skin cancers is not available. Risk factors for skin cancer include increasing age, White race, non-Hispanic ethnicity, personal history of skin cancer, sun exposure, sunburn, and certain types of moles.^{7,12,13} Screening for skin cancer is more effective when conducted by a dermatologist and when the entire body is examined.⁷ According to the National Cancer Institute, there is not enough evidence to suggest that regular screening for skin cancer would save lives.⁷ However, the American Cancer Society recommends regular screenings, including annual skin exams conducted by a health care provider and monthly self-exam.¹⁴

Goal 4: Promote, increase and optimize the appropriate utilization of high quality skin cancer screening and follow-up services.

Objective 4.1: Develop coalitions to build consensus on skin cancer screening recommendations.

Strategy:

1. Convene dermatologists to develop screening recommendations.

Objective 4.2: Expand the current system's ability to provide full body screening exams.

Strategies:

1. Train and/or certify physician and non-physician health care providers to provide full body skin cancer screenings and refer when appropriate.
2. Provide information about full body skin cancer screenings at community health fairs.
3. Determine the extent to which third party payers cover skin cancer screenings, and, if necessary, work to expand reimbursement to include these screenings.

Objective 4.3: Increase the detection of skin cancer.

Strategies:

1. Investigate potential data sources to determine the proportion of people who are currently receiving skin cancer screening services.
2. Educate the public about the importance of and procedures for skin cancer screening, including self and partner exams.

BREAST CANCER

Between 1989 and 1999, 9,174 new cases of breast cancer were diagnosed in Utah.¹ In 1999, there were 984 new cases of breast cancer diagnosed and 183 deaths due to this disease.^{1,4} According to the American Cancer Society, the following screening recommendations are important for the early detection of breast cancer. First, women aged 20 and older should perform monthly breast self exams. Second, women aged 20-39 should have a clinical breast examination by a health care provider every three years. Finally, women aged 40 and older should have a clinical breast exam and mammogram every year.¹⁴ Nationally, mammography rates for women aged 40 and older have more than doubled since 1987, increasing from 29% to 67% in 1998.³ Nearly 69% of all Utah women reported having had a mammogram in the past two years. However, women aged 75 and older were less likely to report having had a mammogram than women aged 65 to 74.⁸ Utah women without health insurance were also less likely to report having had a mammogram in the past two years than were women with health insurance.⁸ In addition, most mammography facilities are located in urban areas, making access difficult for the nearly 70,000 women aged 40 to 69 who lived in rural Utah in 2000.^{15,16}

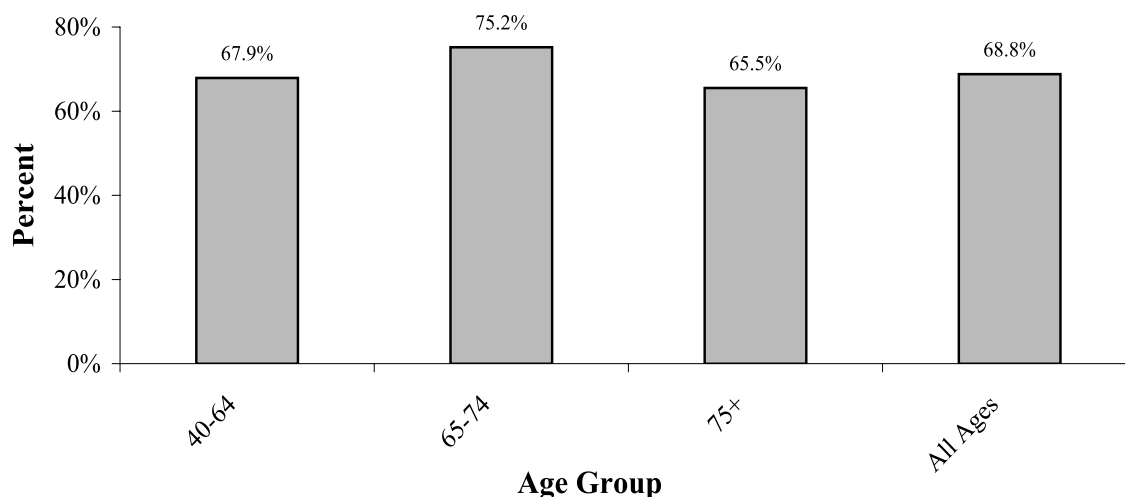
Goal 5: Promote, increase and optimize the appropriate utilization of high-quality breast cancer screening and follow-up services.

Objective 5.1: Increase breast cancer screening rates for those least likely to get regular screening exams.

Strategies:

1. Increase public education to dispel myths about breast cancer risk factors.
2. Identify and resolve emotional barriers to screening.
3. Collaborate with other women's health programs to make screening more convenient and accessible.

Figure 3: The Percentage of Women Aged 40 and Older Who Reported Having Had a Mammogram in the Past Two Years by Age Group, Utah 1998-2000



Source: Utah Behavioral Risk Factor Surveillance System

4. Collaborate with the American Indian community to implement a culturally appropriate intervention.
5. Develop culturally sensitive interventions to reach other high risk populations.

Objective 5.2: Increase the quality and consistency of breast cancer screening services.

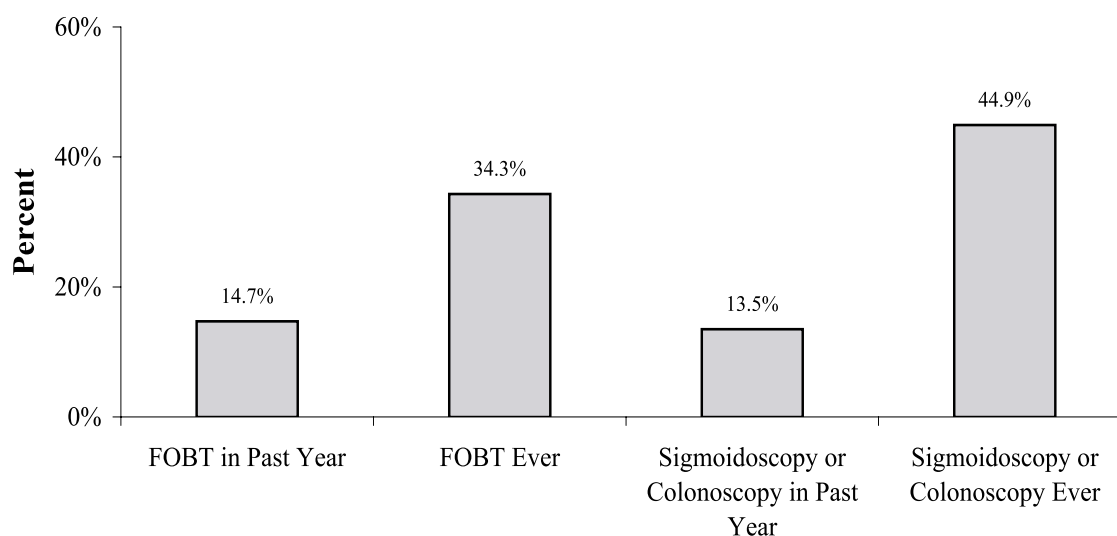
Strategies:

1. Build consensus among radiologists and screening centers regarding the provision of comprehensive breast services, such as clinical breast exams, mammograms, and follow-up care.
2. Encourage radiologists and screening centers to offer expanded hours and transportation.
3. Educate providers about potential screening biases in the elderly population.
4. Collaborate with third party payers to assist primary care providers in tracking compliance with recommended screening intervals and follow-up.

COLORECTAL CANCER

Between 1989 and 1999, 6,290 new cases of colon or rectal cancer were diagnosed in Utah.¹ During 1999, 644 new cases of colon or rectal cancer were diagnosed and 246 deaths occurred due to these cancers.¹⁴ There are several effective screening tests used for the early detection of colorectal cancer, including the fecal occult blood test (FOBT), flexible sigmoidoscopy, double contrast barium enema, and colonoscopy. Controversy exists regarding the best type and frequency of screening test for colorectal cancer.¹⁴ The American Cancer Society recommends yearly FOBT combined with flexible sigmoidoscopy every five years for people aged 50 or older with an average level of risk.¹⁴ Despite these recommendations, in 2000 only 20% of Utahns aged 50 or older reported having had FOBT in the past two years, and only 32% reported having had sigmoidoscopy or colonoscopy in the past five years.⁸

Figure 4: The Percentage of Utahns Aged 50 and Older Who Reported Colorectal Cancer Screening, Utah 1997, 1999, and 2000



Source: Utah Behavioral Risk Factor Surveillance System

Goal 6: Promote, increase and optimize the appropriate utilization of high-quality colorectal cancer screening and follow-up services.

Objective 6.1: Increase screening rates among those aged 50 or older and other high risk groups.

Strategies:

1. Educate the public and health care providers about the need for colorectal cancer screening.
2. Assess the need to train non-physician health care providers to provide endoscopy.
3. Explore Utah participation in the EXACT clinical trial, a study to compare the efficacy of a DNA screening test with FOBT and colonoscopy.

Objective 6.2: Increase dialogue between patients and their primary care providers about colorectal screening options.

Strategy:

1. Work with partners including the Utah Society of Gastroenterologists and the American Cancer Society Colorectal Cancer Task Force to address provider education issues.

TREATMENT



In order to reduce the burden of cancer in Utah, treatment to cure or control the disease must be available, affordable, accessible, and state of the art. Individuals who are newly diagnosed with cancer may not be aware of the full spectrum of treatment options, clinical trials, and support services that are available to them.

Health care providers who routinely treat a large number of cancer patients may provide a higher standard of cancer-directed therapy than those who see fewer cancer patients. The rural nature of many areas in Utah dictates that

some cancer patients may receive some of their cancer-related care from health care professionals who do not see a large number of cancer patients.

Cost is often a barrier to optimal cancer treatment. For the 11% of Utahns who lack health insurance, the cost of cancer treatment can be overwhelming.⁸ Even for those with health insurance, cancer treatment may not be fully covered by all health care plans.

Utah is home to individuals of diverse cultural backgrounds. Lack of understanding of cultural beliefs and practices on the part of health care providers may make cancer therapy more difficult for members of these diverse cultures.

The goals and objectives in this section are related to ensuring that all Utahns who are diagnosed with cancer receive optimal treatment.

Goal 1: Increase awareness of available treatment options and support services among cancer patients in the state of Utah.

Objective 1.1: Provide a free informational pamphlet, which summarizes the broad spectrum of resources available, to every cancer patient in the state of Utah at the time of diagnosis.

Strategies:

1. Identify existing materials that summarize cancer treatment and support resources.
2. Identify individuals and organizations that provide care and services to cancer patients.
3. Distribute these materials to appropriate individuals.

Goal 2: Disseminate information regarding state of the art cancer therapy to health care providers throughout Utah and promote the exchange of ideas regarding optimal management of cancer patients.

Objective 2.1: Collaborate with health care providers throughout the state to develop and support regional tumor boards and meetings of multidisciplinary teams to discuss treatment options for challenging cancer cases.

Strategies:

1. Identify existing tumor boards and explore the possibility of expanding the scope of these boards through strategies like teleconferencing.
2. Identify individuals and organizations that may be willing to participate in tumor boards.
3. Notify individuals and organizations of the tumor board schedule.

Goal 3: *Support efforts to ensure that all cancer patients diagnosed and treated in the state of Utah have the opportunity to receive state of the art therapy and services.*

Objective 3.1: Systematically disseminate information about current standards of cancer care to health care and other cancer-related service providers in Utah.

Strategies:

1. Encourage Utah centers where cancer is diagnosed and treated to seek and maintain accreditation by the American College of Surgeons Cancer Program.
2. Identify organizations that can assist with the implementation of standard treatment guidelines.
3. Encourage the use of National Comprehensive Cancer Professionals treatment standards.
4. Encourage the use of Physicians Data Query standards.
5. Increase awareness of clinical trials.

Goal 4: *Support efforts to ensure that all Utah residents diagnosed with cancer receive state of the art care, regardless of their ability to pay for medical care and other cancer-related services.*

Objective 4.1: Identify programs that provide financial support to cancer patients and their families and disseminate information about these resources to health care providers and cancer patients.

Strategies:

1. Periodically query health insurance providers in Utah to determine coverage of cancer-related treatments and services.
2. Advocate to the state legislature for funding to support cancer treatment and services for those who are uninsured and underinsured.
3. Disseminate this information to health care providers and cancer patients.

Goal 5: *Eliminate cultural barriers to the receiving appropriate cancer therapy.*

Objective 5.1: Ensure that cancer therapy and services are delivered in a culturally appropriate and sensitive manner.

Strategies:

1. Select representatives from diverse cultural communities in Utah to assist in identifying cultural barriers that interfere with the provision of appropriate cancer-related therapy and services, and develop strategies to overcome these barriers.

-
2. Disseminate ethnic health information to health care providers.
 3. Offer education to physicians regarding cultural issues during tumor board meetings.

QUALITY OF LIFE

According to the Institute of Medicine, quality end-of-life care should include pain management, psychosocial support, and timely referral to hospice.¹⁷ Quality of life can be improved for cancer patients and their families by integrating palliative care with treatment throughout the course of the illness.



To ensure the best quality of life for Utahns affected by cancer, the following problems must be addressed. First, cancer patients, their families, and their employers must have realistic expectations regarding the impact of the illness on all aspects of an individual's life. Second, improved assessment methods are needed to allow clinicians to appropriately treat pain and other symptoms. Third, barriers to the provision of adequate symptom management for Utahns with cancer, including cost, public policies, insurance coverage, knowledge, beliefs, attitudes and social norms, must be overcome. Finally, end-of-life care must be made available, accessible, and integral to all aspects of treatment for patients with terminal cancer.

Goal 1: Encourage cancer patients, their families, and their employers to have realistic expectations regarding the patient's quality of life, including physical, emotional, social, spiritual, vocational, and economic issues.

Objective 1.1: Ensure that accurate and appropriate information about cancer and quality of life is available to cancer patients, their families, and their employers.

Strategies:

1. Support state and local organizations in providing educational materials about cancer and quality of life.
2. Collaborate with cancer care agencies to develop a booklet that clearly defines cancer-related terminology.
3. Identify channels for the distribution of the materials listed above.

Goal 2: Institutionalize the consistent use of standardized tools to assess pain and other cancer-related symptoms.

Objective 2.1: Ensure that cancer patients are consistently assessed for pain and other symptoms.

Strategies:

1. Encourage the use of a standardized tool for pain assessment in all care settings.
2. Encourage the use of a standardized tool for cancer symptom assessment in all care settings.
3. Provide institutions that treat cancer patients with evaluative information regarding their agency's ability to address quality of life issues.
4. Advocate for the adoption of quality of life as the sixth vital sign.

Goal 3: Improve access to high quality care and symptom management for cancer patients.

Objective 3.1: Overcome barriers to symptom control and pain management for cancer patients in Utah.

Strategies:

1. Work to ensure that state-regulated insurers are covering effective symptom and pain management therapies.
2. Conduct activities to educate patients and health care professionals about the latest developments in therapies for pain and symptom management.
3. Investigate the potential costs of adding non-pharmacological and palliative therapies to standard insurance coverage.

Goal 4: Ensure that all Utah residents have access to high quality end-of-life care.

Objective 4.1: Ensure that services are in place to provide needed end-of-life care and educate Utahns about these care options.

Strategy:

1. Support and increase awareness of the work of organizations like the Partnership to Improve End of Life Care, Utah's HOPE for Children, Intermountain Health Care, University of Utah, and Utah Hospice to educate the community about end-of-life-care.

SETTING THE AGENDA

To prevent duplication of effort by the Prevention, Early Detection, Treatment and Quality of Life work groups, the UCCCI decided to focus on efforts which address global issues. By determining common areas of need, planned activities will address the entire spectrum of care, including issues identified by the original work groups. After careful consideration, the UCCCI identified three common areas in which efforts will be targeted: 1) Consumer/Patient; 2) Health Care Provider; and 3) Data. The goals, objectives, and strategies for these groups are listed below.



CONSUMER/PATIENT WORK GROUP

Goal 1: Communicate information about available services in the areas of cancer prevention, early detection, treatment and quality of life to patients and consumers.

Objective 1.1: Compile a list of available services across this spectrum.

Strategies:

1. Survey organizations that provide cancer-related services to determine what is being done currently.
2. Compile a list of available services.
3. Revise the list of available services as necessary to address literacy/language needs to increase the usefulness of the list.
4. Make the list of available services accessible to the public on the UCCCI website.

Objective 1.2: Establish a mechanism to update the list of available services.

Strategies:

1. Create forms for submission of information by phone, fax, e-mail or the internet.
2. Organize the list into annual, ongoing and event-specific categories.
3. Periodically contact the individuals/organizations sponsoring the events to review/update their submitted information.

Goal 2: Develop a comprehensive network to educate, enable, and empower patients and other individuals regarding cancer issues.

Objective 2.1: Identify and train a Community Care Volunteer Core (CCVC) whose members will act as brokers to support consumers who are seeking prevention or treatment resources.

Strategies:

1. Identify and recruit individuals who are interested in receiving training to become patient advocates.
2. Gather expertise currently available from peer support groups, such as *Reach to Recovery*, *Man to Man*, or *Cancer Wellness House*.
3. Generate and field test a course for staff and volunteers seeking to become members of the CCVC.
4. Explore the feasibility of credentialing this training to “professionalize” the CCVC membership.

Objective 2.2: Establish a CCVC network.**Strategies:**

1. Identify areas of greatest need where consumers have trouble accessing education, providers, alternatives (e.g. research, alternative therapies).
2. Coordinate efforts to match identified needs with trained CCVC members.

Goal 3: Establish a bureau of speakers for the UCCCI.

Objective 3.1: Invite members of the UCCCI to form a bureau of speakers, thereby increasing the number of qualified presenters and presentations to Utah communities.

Strategies:

1. Assess the strengths and weaknesses of existing speakers bureaus.
2. Create a method to ensure the consistent presentation of data by speakers.
3. Develop appropriate training for speakers.
4. Develop a marketing plan for the speakers bureau to increase demand for presentations.
5. Develop a tracking system to match community needs with speakers.

HEALTH CARE PROVIDER WORK GROUP

Goal 1: Engage health care providers to assist in the implementation of the UCCCI plan.

Objective 1.1: Obtain a commitment from health plans to support the UCCCI plan, develop methods to address objectives outlined in the UCCCI plan, and identify current health plan campaigns in cancer prevention and control.

Strategies:

1. Convene a meeting of medical directors from Utah health plans to discuss the UCCCI, the plan, and implementation of the plan.
2. Obtain input from health plans regarding ways to identify individuals to represent and support the effort.

Objective 1.2: Integrate accepted guidelines into the practice of Utah health care providers.

Strategies:

1. Convene a group of health care providers and health plan administrators to determine accepted cancer care guidelines.
2. Establish a method to profile providers regarding their adherence to accepted cancer care guidelines.

DATA WORK GROUP

Goal 1: Provide appropriate data support for planning and implementing activities that address objectives in the UCCCI plan.

Objective 1.1: Work with the Consumer/Patient and Health Care Provider work groups to determine data needs.

Strategies:

1. Request that additional questions be included in future BRFSS and YRBS surveys to address information gaps for the UCCCI plan objectives.
2. Use the UDOH survey center to collect data to address information gaps in UCCCI objectives.
3. Assist the Consumer/Patient and Health Care Provider work groups in obtaining data for activity planning and dissemination to partners and others.

Goal 2: Expand recruitment and enrollment in prevention-based clinical trials.

Objective 2.1: Create a clinical trials recruitment center to assist with enrollment into prevention-based clinical trials.

Strategies:

1. Convene a group of individuals who are interested in creating a recruitment center for clinical trials.

EVALUATION



As efforts are undertaken to implement this plan, it will be critical to determine the success of these activities. In addition, since members of the UCCCI are key to the successful implementation of the plan, it will be important to evaluate the effectiveness of the UCCCI to determine if valuable resources are being appropriately utilized. The goals, objectives and strategies related to evaluation activities are listed below.

Goal 1: Evaluate implementation activities.

Objective 1.1: Determine the effectiveness of UCCCI activities in addressing the comprehensive cancer control plan objectives.

Strategies:

1. Request that the Consumer/Patient, Health Care Provider, and Data work groups develop an evaluation plan for each strategy.
2. Have each work group conduct an evaluation of its strategies.
3. Report work group evaluation results to the UCCCI.
4. Use the evaluation results to improve activities or to develop new activities.

Goal 2: Evaluate the Partnership of UCCCI.

Objective 2.1: Identify ways to maintain and strengthen the UCCCI.

Strategies:

1. Develop a survey to assess member satisfaction with the UCCCI.
2. Distribute the survey for completion by members at a future UCCCI meeting.
3. Analyze the survey data.
4. Use survey results to identify areas where improvement is needed.
5. Implement changes to improve the UCCCI.

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APPENDIX A: OVERVIEW OF PARTICIPATING ORGANIZATIONS

Altius Health Plans

Altius Health Plans is a Utah based managed care company insuring a population of over 100,000 commercial members. The company provides managed care services and products to Utah employers including health maintenance organization (HMO), dental, mental health, vision, life products with an emphasis on the IPA and group model HMO. Both gate keeper and swing out products for large, medium, and small groups are marketed. The health plan offers full service utilization management and pharmacy management, and several preventive and disease management initiatives.

American Cancer Society

The American Cancer Society (ACS) is the nationwide community-based voluntary health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives, and diminishing suffering from cancer through research, education, advocacy, and service. ACS is headquartered in Atlanta, Georgia, with state Divisions and more than 3,400 local Units. ACS is the largest source of private, nonprofit cancer research funds in the United States. ACS' prevention programs focus on tobacco control, sun protection, diet and nutrition, comprehensive school health education, early detection, and treatment. A variety of service and rehabilitation programs are available to patients and their families. Through its advocacy program, ACS educates policy-makers about cancer and how it affects individuals and families. For more information, call 1-800-ACS-2345 or visit www.cancer.org

Breast Cancer Task Force

The Breast Cancer Task Force (BCTF) promotes the early detection of breast and cervical cancer by providing professional education and mounting public awareness campaigns. The BCTF is housed and staffed by the American Cancer Society. It receives strong support from members including the Utah Cancer Control Program, Utah's twelve local health departments, breast cancer survivors, health care professionals, and interested citizens. Currently, representatives from the AARP, Breast Cancer Coalition of Utah, Cancer Wellness House, Health Insight, Huntsman Cancer Institute, Life After Breast Cancer, local radio and television, Social Security, St. Mark's Health Care Foundation, Susan G. Komen Foundation, Reach to Recovery, YWCA, and local businesses serve as members. Their participation helps to assure communication between all breast cancer organizations. The BCTF spearheads or participates in "Breast Cancer Awareness Month", "Art and Mammograms", "National Mammography Day", "Mother's Day Events", "Tell a Friend", "Free Groceries For Mammograms", and "Life After Breast Cancer". The BCTF has trained over two hundred public and professional volunteer speakers who encounter thousands of Utahns annually. Members of the BCTF helped to persuade the US Congress to pass the Medicaid Breast and Cervical Cancer Treatment Act and were essential in persuading the Utah State Legislature to allocate funds for this Act to assist Utahns during fiscal year 2001-2002.

Cancer Pain Relief-Utah

Cancer Pain Relief-Utah is a cooperative, voluntary effort that provides support for cancer pain management through professional education and advocacy to improve the quality of life of cancer patients. The organization has created a 31 page handbook on cancer pain management, disseminated quarterly newsletters, sponsored statewide pain education programs, developed radio ads about pain

control/management, and is currently creating an analgesic dosing/conversion tool for health care professionals. Membership is open to anyone who wishes to improve public and professional education about cancer pain management and advocate for improved cancer pain relief.

Cardiovascular Health Program, Utah Department of Health

The Cardiovascular Health Program at the Utah Department of Health seeks to assist Utahns in obtaining the knowledge, skills, and access to care they need to make heart healthy choices. Specifically, the Cardiovascular Health Program influences and supports environments and policies that promote heart healthy behaviors in schools, communities, worksites, and high risk populations. The Program's goals mirror the Healthy People 2000 and 2010 objectives in several areas: heart disease and stroke, physical activity, nutrition, access to quality health care services, disability and secondary conditions, education and community based programs, health communication, and public health infrastructure. Program staff have expertise in dietetics, physical activity, health education, health communication, school-based programs, and epidemiology.

Community Nursing Services

Community Nursing Services has been providing home care services since 1929. Programs include pediatrics, high risk pregnancy, elder care, rehabilitation, psychiatric nursing, social work, and hospice care. As the state's oldest non-profit visiting nurse association and hospice, care is provided for adults, children and families coping with a diagnosis of cancer.

Dermatology Research Center

The Dermatology Research Center (DRC) is a company that conducts clinical research trials and drug testing for safety and efficacy prior to Food and Drug Administration approval for diseases and conditions of the skin, hair and nails. DRC participates in drug studies for phase 2, 3, and 4 trials. The Principal Investigator for DRC is Leonard Swinyer, M.D. Dr. Swinyer also operates a private dermatology practice. Thalia Swinyer, RN, CCRC a member of the DRC, provides free lectures on prevention and recognition of skin cancer to public schools, community organizations and health care professionals. She also coordinates and conducts annual free skin cancer screening clinics requested by dermatologists throughout the state.

Ethnic Health Office, Utah Department of Health

The Ethnic Health Office is dedicated to increasing access to health care and eliminating health disparities in Utah's diverse populations. The office serves as a focal point within the Utah Department of Health for planning and coordination of activities and programs for Utah's culturally diverse communities. The Ethnic Health Coordinator and the Bureau of Primary Care, Rural and Ethnic Health support the activities of the Ethnic Health Advisory Committee to the Utah Department of Health.

HealthInsight

HealthInsight is a nonprofit organization whose goal is to help health care providers and professionals improve quality in health care systems of Nevada and Utah. HealthInsight is the Peer Review Organization (PRO) for these states, and, as such, holds the Medicare quality review contract for those two states. The company has been in existence for 29 years and was originally founded by members of the Utah Medical Association. HealthInsight maintains offices in Salt Lake City, Las Vegas, and Reno. The company employs a staff of over 80 people, including physicians, nurses, statisticians, graphic designers,

communication specialists and project managers. The organization's long-term vision is to act as a catalyst in the redesign of the health care systems in Utah and Nevada. To this end, HealthInsight has forged close working relationships with the health care community. HealthInsight staff members serve on the boards of over 20 health organization involved in the health systems in Utah and Nevada. HealthInsight's position in the community is unique among PROs and other organizations in the country.

Huntsman Cancer Institute

The Huntsman Cancer Institute's mission is to understand cancer from its beginnings, to use that knowledge in the creation and improvement of cancer treatments, to relieve the suffering of cancer patients, and to educate the public about cancer risk, prevention and care. The Huntsman Cancer Institute is actively building a cancer control program, which includes all aspects of screening and prevention. This includes educational, behavioral, epidemiological, statistical, basic research, clinical research, translational research, and public service programs.

Intermountain Chapter of the Oncology Nursing Society

The Intermountain Chapter of the Oncology Nursing Society is comprised of a group of approximately 80 registered and advance practice nurses in various oncology care settings along the Wasatch Front. The local chapter provides education to its members and participates in community-based initiatives to improve pain management and end-of-life care. In addition, members participate in committees to support The American Cancer Society's health promotion, early detection, and supportive care programs.

Man to Man

Man to Man programs include public and group education, support groups, and a quarterly newsletter to raise awareness about the early detection and treatment of prostate cancer. Group education and support is conducted in a comfortable and confidential meeting environment to encourage men and their families to discuss their concerns openly and honestly and to share solutions to common problems. In addition, the support groups provide a forum to learn about diagnosis, treatment and life after treatment. A quarterly Man to Man Newsletter is sent to members. Public education about prostate cancer is conducted to promote greater public understanding of prostate cancer, particularly the importance of early detection and treatment.

The Pain, Medicine, and Palliative Care Program, Huntsman Cancer Institute

The Pain, Medicine, and Palliative Care Program is a holistic program offering medical treatments and complementary therapies. The program offers assistance in dealing with the physical, emotional, and interpersonal needs of cancer patients and their families at the time of diagnosis, during or after cancer treatment, or with progressive disease. Services are designed to enhance quality of life for cancer patients and their loved ones while respecting personal values and preferences.

The Partnership to Improve End-of-Life Care in Utah

The Partnership to Improve End-of-Life Care in Utah is a coalition of institutions and individuals who are committed to combining their efforts and expertise toward improving care for persons nearing the end-of-life and their families. This coalition directs its work toward the public, health care professionals, and policy makers.

Planned Parenthood

Planned Parenthood Association of Utah (PPAU) believes that accurate reproductive health information and high quality affordable reproductive health care services should be available to all people in Utah who request them. PPAU's seven statewide health centers, two satellite clinics and fifteen rural health providers serve over 25,000 Utahns each year. Over 70% of the family planning clients served at PPAU are low-income women who receive medical services at little cost through federally subsidized funding. Last year, over 40,000 Utahns received accurate and up-to-date reproductive health information through PPAU education services.

The Prostate Cancer Task Force of the American Cancer Society

The Prostate Cancer Task Force of the American Cancer Society (ACS) in Salt Lake City seeks to promote prostate cancer awareness through education and outreach and bridge the gaps between local organizations with a similar focus. The Task Force has broad representation including multi-disciplinary physicians, nurses, educators, support group leaders, industry representatives, and advocacy experts. Administrative support comes from the ACS, and ACS prostate cancer guidelines are followed.

The Prostate, Lung, Colorectal, and Ovarian Cancer Screening Trial, University of Utah

The Prostate, Lung, Colorectal, and Ovarian Cancer Screening Trial (PLCO Trial) is a randomized, controlled clinical trial assessing the effect of screening on the mortality rate from these cancers. The screening tools being tested are digital rectal exam and PSA (prostate), chest x-ray (lung), flexible sigmoidoscopy (colon), and transvaginal ultrasound and CA125 (ovary).

Public Employees Health Program

The Public Employees Health Program (PEHP) is a quasi-public agency under the direction of the Utah Retirement Systems. PEHP is only available to public employees and employees of educational institutions. PEHP provides a complete range of benefit services, including medical, dental, long term disability and life insurance. PEHP's focus is on providing the highest level of benefits, including cancer management, in the most cost efficient manner possible. Comprehensive innovative benefits combined with excellent customer service is provided. Cancer prevention benefits are available through Healthy Utah and other benefits include screening and treating all forms of cancer.

The Rocky Mountain Cancer Information Service: A Program of the National Cancer Institute

The Cancer Information Service (CIS) is a national resource for information and education about cancer and a leader in translating cancer information into terms that the public can easily understand. The CIS is a program of the National Cancer Institute (NCI), the Nation's lead agency for cancer research. The CIS is comprised of three program areas that educate people about cancer, The Information Service, The Partnership Program, and The Research Initiative. The Information Service provides answers in English and Spanish to questions about cancer, the questions range from prevention and detection to current treatments and new research studies. The Information Services receives questions through a toll-free telephone service (1-800-4-CANCER) and by LiveHelp on the NCI Web sites. The Partnership Program collaborates with other organizations to develop appropriate cancer education programs that reach minority and medically underserved populations. The Research Initiative studies ways to improve the delivery of cancer information to patients, family members, and the public.

Rocky Mountain Candlelighters for Childhood Cancer

Rocky Mountain Candlelighters for Childhood Cancer is a resource for children diagnosed with cancer and their families. This organization provides patient advocacy, educational, emotional, and practical support in a caring and meaningful way.

The Salt Lake Valley Health Department Women's Cancer Screening Services

The Salt Lake Valley Health Department offers free and low cost cancer screening exams, which include clinical breast exams, pelvic exams, Pap smears and vouchers for free mammograms to women between 40 and 64 years of age who have a low to moderate income and are underinsured. Additionally, any woman who is over 64 years of age and does not have Medicare Part B is also eligible for the program. Women who meet the income guidelines and are between 50 and 64 years or are older and do not have Medicare will qualify to receive all of our services at no charge including a voucher for a free mammogram. Women between 40 and 49 years of age will only pay (on a sliding fee scale where the maximum is \$25.00 and the minimum is \$2.50) for the clinical services, and will also receive a voucher for a free mammogram if they meet the same income guidelines.

Susan G. Komen Breast Cancer Foundation

The Susan G. Komen Breast Cancer Foundation is an international organization with a network of volunteers supporting the Foundation's mission of eradicating breast cancer as a life-threatening disease by advancing research, education, screening and treatment. In the past four years, the Salt Lake City Affiliate, which funds community-based breast health education and breast cancer screening projects, has awarded over \$300,000 to specific breast education and screening projects, including several to the Utah Department of Health to augment their screening services to medically underserved women younger than 35 years old.

Tobacco Prevention and Control Program, Utah Department of Health

The Tobacco Prevention and Control Program (TCPC) provides technical expertise, support and coordination at state and community levels to prevent and reduce tobacco use in Utah. Following the Centers for Disease Control and Prevention's recommendations for Best Practices for Comprehensive Tobacco Control Programs, the TPCP has set the following priority areas:

- 1) preventing the initiation of tobacco use among young people;
- 2) persuading and helping adult and teen tobacco users to quit; and
- 3) protecting non-smokers by reducing exposure to environmental tobacco smoke.

To address these areas, the TPCP supports the development of comprehensive tobacco prevention and control programs statewide. Comprehensive programs include school and community based prevention and education, media campaigns, cessation programs, chronic disease programs to reduce the burden of tobacco-related diseases, and enforcement of tobacco laws.

University of Utah College of Nursing

The mission of the University of Utah College of Nursing is to create internationally recognized excellence in nursing and gerontology. The College of Nursing is a community of scholars committed to the discovery, organization, and transmission of knowledge that benefits nursing and the health status of individuals, families, and society. This community of scholars is characterized by integrity and caring, a climate of mutual respect, ethical behavior, and interdisciplinary collaboration. The faculty accepts responsibility for influencing the quality of health care delivery through education, research, scholarly

activities, and service. The mission is undertaken in an environment that respects the individual, fosters diversity, promotes community, creates a desire for life-long learning, and makes excellence an imperative.

Utah Cancer Control Program, Utah Department of Health

The goal of the UCCP is to improve the rate of early detection and follow-up of breast and cervical cancers. The program is directed toward low to moderate income and/or medically underserved Utah women age 50-64. The generous income guidelines have recently been expanded to provide more free mammograms and Pap tests to women whose earnings are higher than the old income limits and to women who may not be able to afford their insurance deductible. The purpose of the program is to detect breast and cervical cancers at their earliest stages, when they are more amenable to treatment and cure.

The screening services are available through the Utah Department of Health at Local Health Departments, Community Health Centers and Indian Health Services throughout the state. It is made possible by a grant from the Centers for Disease Control and Prevention (CDC) and state funding resources. The UCCP has been providing women's cancer screening services for over 25 years. Female health care providers perform the exams and provide assistance in scheduling a mammography appointment. If the results of the screening tests require additional diagnostic evaluation, the UCCP case manager will schedule a visit with one of our participating physicians. UCCP further assists the client from year to year by providing personal reminder letters and phone calls. The Breast and Cervical Cancer Prevention and Treatment Act allows states to provide full Medicaid benefits to qualified women in need of treatment for breast and cervical cancers, including pre-cancerous conditions and early stage cancer. Utah was one of the first six states that completed the approval process. As of July 1, 2001 UCCP began referrals for Medicaid treatment coverage. For more information, call 1.800.717.1811 or visit www.utahcancer.org

Utah Cancer Registry

The Utah Cancer Registry (UCR) was founded in 1966 by Charles Smart, M.D., a Salt Lake City surgeon. The primary purpose of the UCR was to promote public health in Utah by providing services to physicians, hospitals, and the Utah Department of Health. The UCR was founded to serve as an educational resource for physicians and institutions, to stimulate cancer research in Utah, to promote state-of-the-art cancer diagnosis and treatment, and to encourage regular lifetime follow-up of cancer patients. Since 1968, the UCR has served as the official agency for state-mandated cancer reporting. In 1973, the UCR became one of several population-based cancer registries under contract to the Surveillance, Epidemiology and End Results (SEER) program of the National Cancer Institute. For four consecutive years, the UCR has been awarded the North American Association of Central Cancer Registries' Gold Standard Certificate. This award indicates excellence in data quality, completeness and timeliness.

Utah Hospital Cancer Registries

Utah hospital cancer registries maintain data on all patients diagnosed and/or treated at their respective facilities. Lifetime follow-up is provided as a reminder to schedule regular examinations and to provide

accurate survival data. Data are submitted to the Utah Cancer Registry and national cancer agencies. American College of Surgeons accredited hospitals hold regular Cancer Conferences in which the diagnosis, treatment and follow-up care of cancer patients is discussed in a multidisciplinary meeting.

APPENDIX B: COMPREHENSIVE CANCER CONTROL ORGANIZATIONAL INTEREST QUESTIONNAIRE

(Please Complete)

Organization: Respondent Name:
Address:
Telephone: E-mail:

Q-1 What is your or your organization's particular cancer related interest or specialty?

Q-2 Do you believe there is a need for a statewide comprehensive plan for cancer control?
(Circle number)

1. Yes
2. No

(Please explain your answer)

Q-3 What value, if any, would a state plan provide for you and your organization?
(Circle all that apply)

1. Provide a framework to develop your own plan
2. Increase awareness and education in your organization
3. Improve coordination of services between organizations
4. Identify gaps in services
5. Other (Please explain)

Q-4 What could you or your organization provide to assist in the initiative to develop a comprehensive plan for cancer control? (Circle all that apply)

1. Access to cancer data
2. Established network with cancer related organizations
3. Treatment expertise
4. Experience with or access to special populations
5. Prevention expertise
6. Meeting facilities
7. Knowledge regarding patient perspectives
8. Other (please list)

Q-5 Within your organization's strategic plan, is cancer control specifically addressed? (Circle number)

1. Yes
2. No

Q-6 If the answer is "no" to question five, are there plans in the future to develop a strategic plan for cancer control? (Circle number)

1. Yes
2. No

Q-7 In your opinion, what cancer-related issues need to be better addressed in Utah?
(Circle all that apply)

- | | |
|---------------------------|--------------------------|
| 1. Public Education | 5. Improved Surveillance |
| 2. Professional Education | 6. Funding |
| 3. Legislation | 7. Other (Please list) |

Q-8 In your opinion, what is Utah's greatest strength in controlling cancer?

Q-9 In your opinion, what is Utah's greatest weakness in controlling cancer?

Q-10 If you or your organization were to participate in this initiative, what specific benefits would your organization expect to receive?

Q-11 If you could change one thing to improve cancer prevention and control in Utah, what would it be?

Q-12 Would you or someone from your organization be willing to participate on a committee or work group to help develop a comprehensive cancer control plan? (Circle number)

1. Yes
2. No

Q-13 What are the best day(s) and time(s) for you or your representative to meet?
(Circle Answer)

Day(s) -	Mon	Tues	Wed	Thu	Fri
Time(s) -	Before 8:00 a.m.	8-12 am	12-4 pm	After 4:00pm	
No Preference					

Q-14 What other organizations, groups, or individuals do you believe should be involved in this effort.
(Please list)

Organization	Contact	Telephone
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- 1.
- 2.
- 3.

THANK YOU FOR YOUR TIME!

APPENDIX C: RESOURCES FOR COLLABORATION AND IMPLEMENTATION

Primary Prevention Resources

Active for Life Program, American Cancer Society (ACS)
5 a Day, UDOH/5 a Day Association
Cardiovascular Health Alliance, Utah Department of Health (UDOH)
Coalition for a Tobacco-Free Utah, UDOH
Cowboys Against Tobacco
Cowboy Ted's Kids Club
Dash, Dermatology Research Center
E.N.D. (Ending Nicotine Dependency) Youth Cessation Program, UDOH
Freedom From Smoking
Freshstart Plus, ACS
Healthier You 2002, Salt Lake Organizing Committee for the Olympic Winter Games
Generation Fit Program, ACS
Guide to Complementary and Alternative Cancer Methods, ACS
Hunstman Cancer Institute
Make Yours a Freshstart Family, ACS
Meeting Well Program, ACS
Poison Control Center, University of Utah College of Pharmacy
Slip Slap Slop Campaign, ACS
Smokeless States Project, Robert Wood Johnson Foundation
Straight Talk, Utah Medical Association
TATU (Teens Against Tobacco Use), American Lung Association
The Truth about Tobacco Media Campaign, UDOH
Utah Health Plans
Utah Hospitals
Youth Cessation Hotline, UDOH

Early Detection Resources

American Associations of Retired Persons
Cervical Cancer Screening Services, UDOH/Utah's Local Health Departments
Health Care Provider Talking Points, Intermountain Health Care
Indian Walk in Center
Indian Health Services
Massage Therapy and Cosmetology Licensing Programs
Prostate Cancer Task Force, ACS
School Districts and Utah State School Health Programs, Office of Education

Treatment Resources

American College of Surgeons

Federal, State, and Private Funding Sources

Professional Organizations

TRIAD Committee, ACS/Utah Cancer Registry

Utah Health Plans

Quality of Life Resources

ACS

Cancer Care Program, Huntsman Cancer Institute

Cancer Pain Relief Utah

Demonstration Project, Health Care Finance Administration

Learning Center, Huntsman Cancer Institute

Palliative and Supportive Care Services, Intermountain Health Care

Partnership to Improve End of Life Care

Utah Cancer Control Program, UDOH

Utah's HOPE for Children

Utah Hospice Organization

University of Utah

APPENDIX D: TERMS AND DEFINITIONS

5 a day: A national program designed to communicate the health benefits of eating at least 5 servings of fruits and vegetables daily as part of a low-fat, high-fiber diet.

Alternative therapy: Also known as alternative medicine or complementary medicine. These various systems of healing, including homeopathy, herbal remedies, hypnosis, acupuncture, and osteopathy, operate on different principles than that of traditional western medicine.⁸

Age-adjusted mortality rate: Age-adjustment allows rates to be compared between population groups with different age distributions. Age-adjusted rates are usually expressed per 100,000 individuals per year.⁹

Behavioral Risk Factor Surveillance System (BRFSS): An ongoing random-digit dialed telephone survey of adults concerning health-related behaviors. This survey is conducted in all U.S. states and data are weighted to be representative of the population.

Body mass index (BMI): Weight in kilograms divided by height in meters squared. This calculation is used to describe weight status such as underweight, overweight, or obese.¹⁹

Bureau of Speakers: A group of individuals who have been trained to offer presentations on a topic.

Cancer: A group of disease which are characterized by abnormal and uncontrolled cell division.¹⁸

Colonoscopy: A test for colorectal cancer in which the entire rectum and colon are examined with a fiberoptic instrument.¹⁸

Environmental tobacco smoke: A mixture of smoke that is given off by the burning end of a cigarette, pipe, or cigar and exhaled from a smoker's lungs. Also called ETS, secondhand smoke, and passive smoking.²⁰

Fecal Occult Blood Test (FOBT): A test for colorectal cancer in which stool is examined for blood.¹²

Gold Medal Mile: Sponsored by the Salt Lake Organizing Committee's A Healthier You 2002. One-mile walks designed to encourage Utahns to become more physically active.

Gold Medal Schools: A statewide program sponsored by the Utah Department of Health, the State Office of Education, and the Salt Lake Organizing Committee's A Healthier You 2002. This program encourages policies that promote increased physical education and proper nutrition and the necessary environmental changes needed to increase physical activity and proper nutrition.

Health care provider: Health professionals including physicians, nurses, dentists and others who practice medicine including disease prevention, detection, treatment, and rehabilitation.

Incidence: The number of newly diagnosed cases of a disease occurring in a given population during a specific period of time. Incidence rates are usually expressed as the number of new cases per 100,000 persons in a population.⁹

Mammogram: A low-dose x-ray of the breast used for the detection of breast cancer.¹⁸

Mortality rate: A rate expressing the proportion of a population who die of a disease or of all causes during a given period of time. Mortality rates are often expressed as the number of deaths per 1,000 or 100,000.⁹

Obese: Body mass index of 30 or above.¹⁹

Overweight: Body mass index of 25-29.¹⁹

Palliative Care: In 1990, the World Health Organization defined palliative care as the “active total care of patients whose disease is not responsive to curative treatment. Many aspects of palliative care are also applicable earlier in the course of the illness, in conjunction with anticancer treatment.”²¹

Papanicolaou test (Pap test, Pap smear): A test for cancer or precancerous conditions of the cervix in which cells are scraped from the cervix and examined under a microscope.¹⁸

Primary Prevention: An action taken to prevent the development of a disease in a person who does not already have it.⁹

Prostate-specific antigen (PSA): An enzyme excreted by the prostate. A blood test for this enzyme is used to detect prostate cancer, since blood levels of this enzyme are known to increase in men with prostate cancer.¹⁸

Secondary prevention: An action taken to identify a disease at an early stage in its development.⁹

Sigmoidoscopy: A test for colorectal cancer in which the rectum and sigmoid colon are examined with a fiberoptic instrument.¹⁸

Talking points: Written documents of suggested discussion points to guide providers when discussing specific topics with patients.

Tertiary prevention: Action taken to limit disability and rehabilitate when a disease has already occurred.²²

UCCCI: The Utah Comprehensive Cancer Control Initiative.

Youth Risk Behavior Survey (YRBS): A school-based survey conducted every other year to assess the prevalence of health risk behaviors among high school students. It includes a national survey conducted by the CDC as well as state, territorial, and local school-based surveys.